# Perinatal Mortality in Ireland

NATIONAL PERINATAL
EPIDEMIOLOGY CENTRE

ANNUAL REPORT 2013

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**Citation for this report:**
Manning E, Corcoran P, Meaney S, Greene RA, on behalf of the Perinatal Mortality Group. Perinatal Mortality in Ireland Annual Report 2013. Cork: National Perinatal Epidemiology Centre, 2015.

Funded by the Irish Health Service Executive

Printed by Hackett Reprographics, 5 Copley St., Cork

ISSN 2009-678X (Online) ISSN 2009-6771 (Print)

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# Contents

# List of figures

# List of tables

# Acknowledgements

Welcome to the 2013 Perinatal Mortality Report from the National Perinatal Epidemiology Centre (NPEC). The Report adds to the series of outputs from the NPEC multidisciplinary specialist Perinatal Mortality Group addressing the investigation of perinatal mortality in Ireland from a clinical perspective. The members of the Group are listed in Appendix A. In collaboration with the Perinatal Mortality Group, the NPEC has collected and analysed anonymised perinatal mortality data from Irish maternity units since 2008. Results of these clinical audits have been reported in successive annual NPEC reports.

An important advancement within the NPEC has been the development and implementation nationally in 2011 of a comprehensive data collection tool and classification system for perinatal deaths. I would like to acknowledge with thanks the intellectual input of the Perinatal Mortality Group in guiding this programme.

It gives me great pleasure to present the third NPEC Perinatal Mortality Report on data collated using this new system on perinatal deaths occurring in Ireland in the year 2013. As with our previous report, expert commentary was invited on a specific topic of perinatal care and services in Ireland. I would like to thank Dr Keelin O'Donoghue, Senior Lecturer, Department of Obstetrics and Gynaecology, UCC and Consultant Obstetrician at the Cork University Maternity Hospital for her invited commentary on 'The Impact of Stillbirth' in this report.

Of note, this is the first Perinatal Mortality Report published by the NPEC since it aligned with the National Office of Clinical Audit (NOCA). Our participation in NOCA ensures a process by which we can close the audit loop. This begins with bench marking clinical care with identified standards, such as those set by the National Clinical Programme in Obstetrics and Gynaecology, the Institute of Obstetrics and Gynaecology and the Faculty of Paediatrics, and ends with implementing change for the improvement of patient safety and quality of care. The NOCA Governance Board endorsement of this Report is in Appendix B.

Measurement of the outcome of care is central to the development of safe and high quality health care services. Support from all Irish maternity units is instrumental in the success of this important national programme. On behalf of the NPEC, I extend my sincere thanks and appreciation to the many midwives, obstetricians, paediatricians, pathologists and administration staff who have supported and contributed data to this audit. In particular, we at the NPEC gratefully acknowledge the commitment of designated

unit co-ordinators (see Appendix C) who co-ordinate the collection of perinatal mortality at unit level. This national audit on perinatal mortality would not be possible without their dedicated support and co-operation.

I would also like to acknowledge the NPEC Advisory Group (latterly NPEC Governance Committee) for their intellectual input as the Centre continues to grow and evolve. Members represent a diverse range of key stakeholders from maternity units and universities throughout the country, and their support is instrumental to the success of the Centre. With the support of this group, we have developed the NPEC Data Access Policy for researchers wishing to access anonymised data currently maintained in the NPEC.

Lastly, I would like to thank the staff of the NPEC for their hard work and dedication to the mission of the Centre, in translating clinical audit data and epidemiological evidence to inform maternity services in Ireland.

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# Executive summary

This is the third report of the national clinical audit on perinatal mortality in Ireland using the NPEC data collection tool and classification system. Anonymised data were reported by the 20 Irish maternity units on a total of 500 perinatal deaths occurring in 2013 arising from 69,146 births of at least 500g birthweight or at least 24 weeks gestation. Stillbirths, early neonatal and late neonatal deaths accounted for 301 (60.2%), 162 (32.4%) and 37 (7.4%) of the 500 deaths, respectively.

The perinatal mortality rate was 6.7 per 1,000 births in 2013; corrected for congenital malformation, the rate was 4.4 per 1,000 births; the stillbirth rate was 4.4 per 1,000 births; and, the early neonatal death rate was 2.4 per 1,000 live births.

Applying the more restrictive World Health Organization guideline of reporting perinatal deaths with a birthweight of at least 500g irrespective of gestation, as the Healthcare Pricing Office does in reporting national perinatal statistics,there were 273 stillbirths (3.9 per 1,000 births) and 158 early neonatal deaths (2.3 per 1,000 live births) in 2013.[1]

International comparisons are hampered by variation in definitions, availability of screening programmes for congenital anomalies and national legislation on abortion. Nevertheless, the Irish stillbirth rate is low in the European context.

After correction for congenital malformation, the perinatal mortality rate across the 20 Irish maternity units ranged from 1.1 to 8.1 per 1,000 births. This shows a greater level of variation than was observed in 2011 and 2012.

Major congenital anomaly was the primary cause of death in almost one in four (n=69, 22.9%) of the 301 stillbirths that occurred in 2013. There was a chromosomal disorder in almost half of the 69 stillbirths due to congenital anomaly (n=33, 47.8%).

A placental condition, most commonly classified as maternal vascular malperfusion, was the main cause of death of almost one in four stillbirths (n=66, 21.9%). One in ten stillbirths (n=30, 10.0%) were due to mechanical factors, the vast majority of which were due to the umbilical cord being around the baby's neck or another entanglement or a true knot in the umbilical cord. For approximately one in four stillbirths (n=71, 23.6%) the cause of death was unexplained. While this is significantly lower than the proportion previously reported as unexplained using the Wigglesworth Classification System, it is marginally higher than in the two previous years.

Major congenital anomaly was the primary cause of death of more than half (n=92, 56.8%) of the 162 early neonatal deaths and approximately half of late neonatal deaths (n=18, 48.6%). Respiratory disorders were the other main cause of early (31%) and late (23%) neonatal deaths. The vast majority of these deaths were classified as due to severe pulmonary immaturity.

In Ireland in 2013, an autopsy was undertaken following 48.5% of stillbirths (n=144 of 297, unknown for four cases) and 39.6% of early neonatal deaths (n=63 of 159, unknown for three cases). These rates are higher than in the UK as a whole in 2013 (full autopsy for 44.7% of stillbirths and 29.6% of early neonatal deaths).[2]

1 Healthcare Pricing Office. (2014) Perinatal Statistics Report 2013. Dublin: Health Service Executive.
For 2013, the National Perinatal Reporting System (NPRS) at the Healthcare Pricing Office (HPO), reported 277 stillbirths (4.0 per 1,000 births) and 159 early neonatal deaths (2.3 per 1,000 live births). The NPRS is a national data system based on data collected from Part 3 of the Birth Notification Form (BNF01) which is used to notify local registrars of all live births and stillbirths, including planned domiciliary births, occurring in Ireland (see www.hpo.ie). NPEC is currently in consultation with the HPO to consolidate any data differences e.g. definitions, in reporting to both systems.
2 Manktelow BM, Smith LK, Evans TA, Hyman-Taylor P, Kurinczuk JJ, Field DJ, Smith PW, Draper ES, on behalf of the MBRRACE-UK collaboration. Perinatal Mortality Surveillance Report UK Perinatal Deaths for births from January to December 2013. Leicester: The Infant Mortality and Morbidity Group, Department of Health Sciences, University of Leicester. 2015.

The value of placental examination in determining cause of perinatal death is well documented.[3] In 2013, placental histology examinations were conducted for almost all stillbirths (n=292, 97.0%) and for 84.6% of early neonatal deaths (n=137). This represents an increase in the rate of placental histology examination over recent years. Following placental histology examination, specific placental conditions were diagnosed in 60.3% of stillbirths and 47.4% of early neonatal deaths.

The age profile of mothers who experienced perinatal loss in 2013 differed somewhat from that of all mothers who gave birth in the country that year. Close to 60% of the population who gave birth in 2013 were aged 25-34 years whereas mothers who experienced perinatal loss were less often in this age range (48.2%).

In terms of ethnicity and occupation, while the numbers involved were small, ethnic minorities and the unemployed were overrepresented in the mothers who experienced perinatal deaths: this is similar to findings in 2012. Monitoring the socio-economic status of the pregnant population in Ireland is challenging as these data are not routinely captured in Irish maternity records but further efforts must be made if we are to better understand how social disadvantage impacts on perinatal outcomes.

Smoking status of the mothers at their time of booking was recorded for 421 (90.9%) of the 463 women. Of these, 75 (17.8%) were smokers– similar to the 17.2% prevalence reported for 2012. Most were smoking at least 10 cigarettes per day (n=41 of 71, 57.7%; quantify smoked unknown for four cases). Information on smoking in late pregnancy was available for 44 of the 75 smokers (58.7%); eight (18.2%) stopped smoking during pregnancy. There were four cases with a documented history of alcohol abuse and seven women had a documented history of drug abuse.

Body mass index (BMI) was available for 77.8% (n=360) of women who experienced perinatal loss in 2013, almost identical to the 78.2% rate of recording for 2012. The BMI of 46% of those mothers in 2013 was in the healthy range (18.5-24.9kgm-2) as was the case in 2011 and 2012. In each of the three years, 53% of the mothers who experienced perinatal loss were either overweight or obese albeit with fluctuation in the distribution within these two groups.

Over two thirds of the mothers who experienced perinatal loss in 2013 had at least one previous pregnancy (326 of 463, 70.4%). In terms of parity, women who experienced perinatal loss were similar to the population of women who gave birth in 2013. However, as in previous years, they were more likely to be Para+ 3 compared to the general population of women delivered.

There were 46 perinatal deaths from multiple births, making up 9.9% of all perinatal deaths in 2013. This is nearly three times the proportion of multiples among all births in 2013 (3.8%).[4] Consequently, the perinatal mortality rate of 17.6 per 1,000 multiple births was nearly three times the national perinatal mortality rate.

Twenty-nine mothers (7%) were admitted to the high dependency unit (HDU) following the delivery. Six mothers (1.3%) were admitted to the intensive care unit.

As well as findings from the clinical audit itself, the invited commentary contributed to this year's report by Dr Keelin O'Donoghue, Consultant Obstetrician and Gynaecologist Cork University Maternity Hospital, is focused on the impact of stillbirth. Consideration is given to the impact on parents and families, healthcare professionals and broader society.

3 Korteweg FJ, Erwich JJ, Timmer A, van der Meer J, Ravise JM, Veeger NJ, Holm JP. Evaluation of 1025 fetal deaths: proposed diagnostic workup. Am J Obstet Gynecol 2012 206:53.e1-53.e12
4 Healthcare Pricing Office. (2014) Perinatal Statistics Report 2013. Dublin: Health Service Executive.

The importance of research, clinical audit, confidential enquiry and raising public awareness is highlighted.

There were 37 late neonatal deaths in 2013 reported to the NPEC, a number that is consistent with the annual number of late neonatal deaths reported by the Central Statistics Office in recent years. At the time of writing finalised figures for late neonatal deaths in 2013 were not yet published by the Central Statistics Office (CSO). Currently in Ireland, there is no formal system by which maternity units are notified of the outcomes for infants referred to paediatric units, which could result in underreporting of late neonatal deaths to the NPEC. We are working with colleagues in the relevant hospitals (maternity and paediatric) to address this issue.

In summary, the findings of this national clinical audit of perinatal mortality highlight the inherent need for on-going audit in order to identify key factors impacting on adverse perinatal outcomes.

Perinatal mortality is a potential pregnancy outcome for any woman. There is a need for a public awareness programme around perinatal mortality with an understanding that its prevention begins prior to the maternity period. Potential parents must be aware of modifiable risk factors in order to improve their health and lifestyle before pregnancy.

# Recommendations

**Based on the findings of this report, the NPEC Perinatal Mortality Group makes the following recommendations.**

- The establishment of a Confidential Enquiry for Stillbirth and Neonatal deaths should be considered in order to enhance the lessons which may improve care. A suitable starting point may be a retrospective in-depth review of a case series of unexpected perinatal deaths associated with intrapartum events. Such a review would impart additional information on quality of care.

- Improved antenatal detection of fetal growth restriction with timely delivery is a preventative strategy to reduce perinatal mortality. The generation of customized birth weight centile charts for every woman during pregnancy is recommended and concomitantly, staff should be trained to plot symphysial fundal height and scan weight estimates in order to reduce stillbirths in Ireland.

- The establishment of a national perinatal pathology service, in association with the Faculty of Pathology, would facilitate an agreed approach to classification of autopsy, placental histology and cytogenetics and would provide equal access to review for all perinatal deaths nationally. A positive initial step would be the development of a standardised national reporting proforma for placental histology.

- The submission of anonymised placental histology reports on perinatal death to the NPEC as part of this audit. This would facilitate standardised interpretation and classification of placental conditions.

- Further research exploring factors impacting on autopsy rates, particularly in the case of neonatal deaths, is warranted.

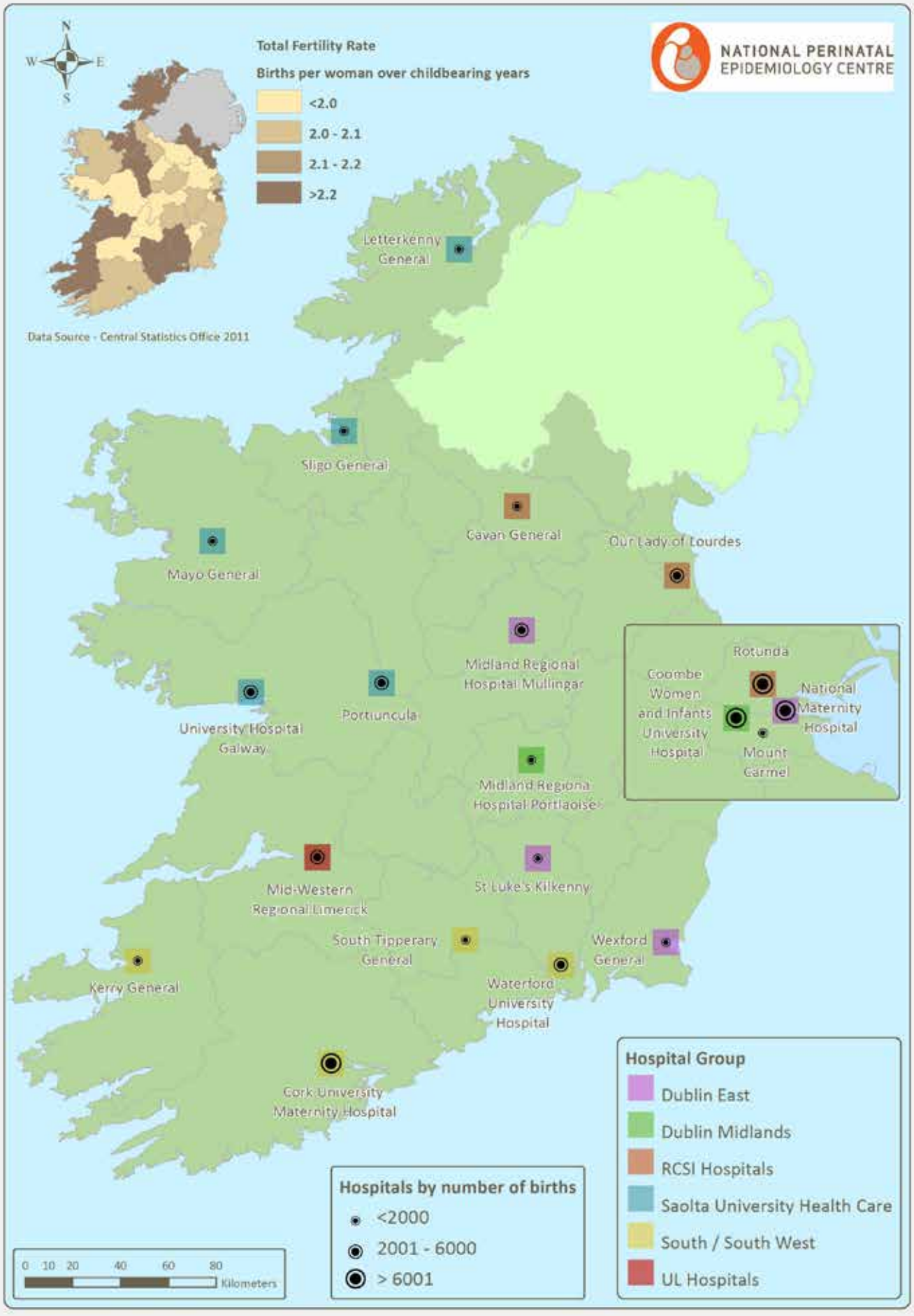
- A structured notification system should be developed to improve inter hospital communication when neonatal or infant deaths occur in a tertiary or paediatric centre.

- Collation of an agreed national dataset for maternity services in order to facilitate examination of factors influencing adverse obstetric outcomes including perinatal mortality. This may be achieved through the implementation of the Maternal Newborn - Clinical Management System.

- Robust clinical audit of perinatal outcomes in all maternity units in Ireland is vital for patient care. Such audit requires the protected time of clinical staff. Funding should be provided by the Health Service Executive to ensure that staffing levels allow protected time for clinical audit.

- A multidisciplinary approach, including perinatal pathology, is recommended in the audit of perinatal deaths at unit level.

- All maternity units should continue to collect and submit data on perinatal deaths to inform the maternity services through the NPEC national audit on perinatal mortality. This should include all neonatal deaths regardless of gestational age or weight at birth. In the case of stillbirths, all babies from 24 weeks gestation or with a birthweight of ≥500g should be reported.


NATIONAL PERINATAL EPIDEMIOLOGY CENTRE
Total Fertility Rate
Births per woman over childbearing years
<2.0
2.0 - 2.1
2.1 - 2.2
>2.2
Data Source - Central Statistics Office 2011
Letterkenny General
Sligo General
Cavan General
Our Lady of Lourdes
Mayo General
Midland Regional Hospital Mullingar
Rotunda
Coombe Women and Infants University Hospital
National Maternity Hospital
Mount Carmel
Portiuncula
University Hospital Galway
Midland Regional Hospital Portlaoise
Mid-Western Regional Limerick
St Luke's Kilkenny
South Tipperary General
Wexford General
Kerry General
Waterford University Hospital
Cork University Maternity Hospital
Hospitals by number of births
<2000
2001 - 6000
> 6001
Hospital Group
Dublin East
Dublin Midlands
RCSI Hospitals
Saolta University Health Care
South / South West
UL Hospitals
0 10 20 40 60 80
Kilometers

# Methods

## Data recording

In 2013, there were 20 maternity units in Ireland. Anonymised data on the perinatal deaths that occurred between January 1 and December 31 2013 were collected from all 20 units using a standardised notification form (see Appendix D). This detailed notification form, implemented nationally in 2011, was based on the validated Centre for Maternal and Child Enquiries (CMACE) Perinatal Death Notification Form[5] and has been endorsed by the Clinical Advisory Group at the Institute of Obstetrics and Gynaecology, the Faculty of Paediatrics and the Health Service Executive (HSE) National Obstetric Programme Working Group.

Figure 1 illustrates the flow of information involved. To ensure accuracy of information, missing or incomplete data were sought from respective maternity units.

## Definitions and terminology

While individual units define perinatal cases similarly, there is some variation. To allow for comparison across all units the NPEC used the following definitions for the current report:

Stillbirth: Baby delivered without signs of life from 24 weeks gestation or with a birthweight ≥500g.[6]

Early neonatal death: Death of a live born baby occurring within 7 completed days of birth.

Late neonatal death: Death of a live born baby occurring after the 7th day and within 28 completed days of birth.

Live birth: Live birth refers to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life - e.g. beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles - whether or not the umbilical cord has been cut or the placenta is attached. Each product of such a birth is considered live born.[7]

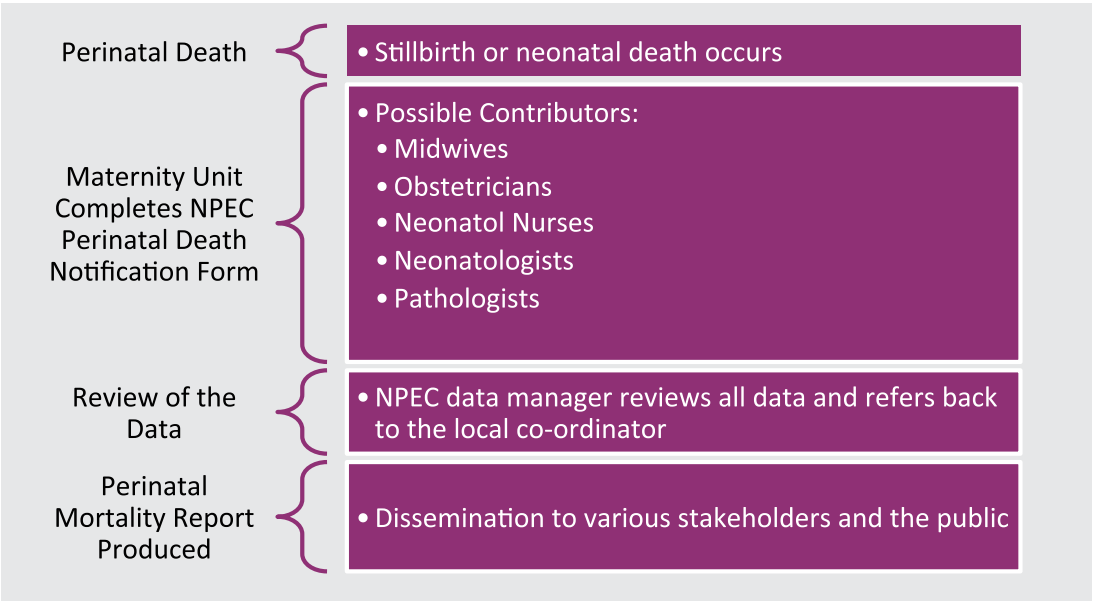



Figure 1: Flow of information in the NPEC data collection process.

5 Centre for Maternal and Child Enquiries (CMACE) (2010) Perinatal Mortality 2008: United Kingdom. London: CMACE
6 Stillbirths Registration Act, 1994.
7 World Health Organisation. Available at: http://www.who.int/healthinfo/statistics/indmaternalmortality/en/

Total births: For the purpose of calculating perinatal mortality rates, the denominator used was the number of births (live birth and stillbirths) from 24 weeks gestation or birthweight ≥500g.

Stillbirth rate: Number of stillbirths per 1,000 births (live births and stillbirths from 24 weeks gestation or weighing ≥500g). In accordance with the World Health Organisation reporting guidelines, the Irish Healthcare Pricing Office perinatal statistics report on stillbirths with a birthweight ≥500g.[8] For consistency, we also report the stillbirth rate using the criterion of birthweight ≥500g.

Neonatal death rate: Number of neonatal deaths per 1,000 live births (from 24 weeks gestation or weighing ≥500g). The Irish Healthcare Pricing Office perinatal statistics report on early neonatal deaths with a birthweight ≥500g. For consistency, we also report the neonatal death rate using the criterion of birthweight ≥500g.

Overall perinatal mortality rate (PMR): Number of stillbirths and neonatal deaths per 1,000 births (live births and stillbirths from 24 weeks gestation or weighing ≥500g). Again for consistency with the Irish Healthcare Pricing Office reporting of perinatal statistics, we also report the neonatal death rate using the criterion of birthweight ≥500g.

Corrected PMR: Perinatal mortality rate excluding perinatal deaths associated with or due to a congenital malformation.

Booking: Some data sought by the NPEC Perinatal Death Notification Form relate to the time of booking. Booking in this regard relates to the mother's first antenatal visit at the maternity unit.

In utero transfer: The NPEC Perinatal Death Notification Form records the intended place of delivery at the time of the mother's first antenatal visit and the intended place of delivery at onset of labour. For cases where the intended place of delivery at booking differed from the intended place of delivery at onset of labour it was presumed that the care of the mother was transferred in utero, i.e. the pregnant woman was transfered in utero to the care of another maternity unit where her baby was delivered. From 2016, in utero transfer will be ascertained by a specific question on the NPEC Perinatal Death Notification Form.

Parity: The number of completed pregnancies, whether live birth or stillbirth, of at least 24 weeks gestation or with a birthweight ≥500g. We refer to parity prior to the pregnancy that resulted in a perinatal loss in 2013.

Gravida: The number of times the mother has been pregnant, irrespective of duration. We refer to gravida prior to the pregnancy that resulted in a perinatal loss in 2013.

Classification of abnormal placental histology: Abnormal placental findings have been classified and are presented under the following broad categories: maternal vascular malperfusion, fetal vascular malperfusion, cord pathology, placental maturation defect, chorioamnionitis, villitis and other. This is in keeping with recommendations in a forthcoming publication from an international consensus meeting of pathology. It is envisaged that this will optimise classification of placental conditions causing or contributing to perinatal loss.

## Classification of death

The NPEC data collection form requests contributors to identify maternal, fetal and neonatal conditions, using specific categories, which caused or were associated with the death. The unit contributor is also requested to assign the principal cause of death with reference to the post mortem and placental pathology if performed. Guidance and definitions for completing specific categories are described in Appendix E. Briefly described; categories include both pathophysiological entities and clinical conditions present at

8 Healthcare Pricing Office. (2014) *Perinatal Statistics Report 2013.* Dublin: Health Service Executive.

time of death including placental pathology and Intra-Uterine Growth Retardation (IUGR). Classification of stillbirths was made using the NPEC maternal and fetal classification system. In the case of neonatal deaths, the NPEC neonatal classification system was used to attribute the main neonatal cause of death and the NPEC maternal and fetal classification system was used to identify the underlying obstetric condition/sentinel event associated with the death. A notable difference in the NPEC neonatal classification system is that neonatal deaths occurring after 22 weeks gestation, previously attributed to prematurity, would most often be captured under the subcategory of 'severe pulmonary immaturity'.

## Rate calculations

To assess perinatal mortality, overall and unit-specific perinatal mortality rates (PMRs) per 1,000 births and corresponding 95% confidence intervals based on the normal approximation of the Poisson distribution were derived. Stillbirth, neonatal and corrected PMRs, which exclude deaths associated with or due to a congenital malformation, were also calculated. Denominator data on the number of live births and stillbirths were provided directly by individual maternity units. Perinatal deaths are included in a maternity unit's rate if the baby was delivered in the maternity unit or if the unit was the intended place of delivery but the baby was born before arrival. Of the reported perinatal deaths in 2013, there were six cases that were not included in the rate of a maternity unit. These were cases where the mother had not received antenatal care from a maternity unit or a self-employed community midwife but presented to a unit after unattended delivery in the community.

## Funnel plots

Variations in PMRs between maternity units could potentially be due to random chance or reflect differences in baseline characteristics of the childbearing population. For this reason, funnel plots were used to assess performance outcomes for individual units in comparison to the overall average.[9] In brief, the plot is a scatter diagram of individual maternity unit mortality rates against the number of births within that unit. The overall mortality rate is indicated by the solid straight line and the corresponding 95% confidence interval is indicated by the curved dashed line. The confidence interval is wider for smaller units, which are more prone to variable estimates and gradually narrows as the unit size increases, hence, giving the diagram a 'funnel' shape. Maternity units with mortality rates lying outside the 95% confidence interval are statistically significantly different from the overall average. In general, one of 20 units would be expected to lie outside the 95% confidence interval by chance alone.

## Birthweight centile

As with previous reports, we have produced charts in this year's report to highlight the issue of failure of fetal growth in utero in relation to the stillbirths and early neonatal deaths that occurred in Ireland in 2013. To do so, we used the Gestation Related Optimal Weight (GROW) software[10] and coefficients derived from the multiple regression analysis of data on 11,072 births in six maternity units in Dublin, Galway, Limerick and Belfast in 2008-2009.[11]

The regression analysis determined the Term (i.e. 40 weeks) Optimal Weight (TOW) in Ireland to be 3,490.7g. The normal range (i.e. the range from the 10th centile weight to the 90th centile weight) around the TOW was then calculated and the recommended

9 Spiegelhalter D. (2002) Funnel plots for institutional comparison. *Quality and Safety in Health Care;* 11(4):390-91.
10 Gardosi J, Francis A. Customised Weight Centile Calculator. GROW version 6.6, 2013 Gestation Network, www.gestation.net
11 Unterscheider J, Geary MP, Daly S, McAuliffe FM, Kennelly MM, Dornan J, Morrison JJ, Burke G, Francis A, Gardosi J, Malone FD. The customized fetal growth potential: a standard for Ireland. Eur J Obstet Gynecol Reprod Biol 2013; 166(1):14-7

proportionality growth function was applied to the TOW, the 10th centile term weight and the 90th centile term weight in order to determine the optimal weight and normal range at all gestations (21-44 weeks for the stillbirths and early neonatal deaths in Ireland in 2013). These steps are described in detail in the GROW documentation.

Customised birthweight centiles were also derived using the GROW software. There was a high level of missing data for maternal height and weight with one or both unknown for 125 (27.0%) mothers. For these cases, we used the median height and weight of the mothers with complete data. The GROW software also provides estimated customised birthweight centiles in cases with missing data. Ultimately, customised birthweight centiles were calculated for 459 of the 463 mothers (99.1%).

# 1. Main findings

## Perinatal mortality rate

This section of the report provides details of the perinatal mortality rate (PMR), maternal and infant characteristics and autopsy uptake. In line with previous reports, the findings provided in this section relate to stillbirths and early neonatal deaths only. Separate sections are then provided for stillbirths, early neonatal deaths and late neonatal deaths describing clinical management and the main cause of death based on the NPEC Classification System.

Current legislation on stillbirth registration in Ireland is based on the criteria of birthweight ≥500g or gestation at delivery ≥24 weeks. Using these criteria, the 20 Irish maternity units reported 69,146 births, of which 500 were subsequently classified as perinatal deaths. Stillbirths, early neonatal and late neonatal deaths accounted for 301 (60.2%), 162 (32.4%) and 37 (7.4%) of the 500 deaths, respectively.

The reporting guideline of the World Health Organization, adopted by the Irish Healthcare Pricing Office in their publication of national perinatal statistics, recommends the more limited criterion of birthweight ≥500g. In 2013, the 20 Irish maternity units reported 69,115 births weighing ≥500g of which 468 were subsequently classified as perinatal deaths. Stillbirths, early neonatal and late neonatal deaths accounted for 273 (58.3%), 158 (33.8%) and 37 (7.9%) of the 468 deaths, respectively.

Thus, it can be seen that while broadening the inclusion criteria has a negligible impact on the total number of births, it increased the number of stillbirths and early neonatal deaths by 10.3% (from 273 to 301) and 2.5% (from 158 to 162), respectively. This is also evident for the rate of each perinatal mortality outcome as detailed in Table 1.1.

The stillbirth rate associated with the criteria of birthweight ≥500g or delivery gestation ≥24 weeks was 4.4 per 1,000 births and the early neonatal death rate was 2.4 per 1,000 live births compared respectively to 3.9 and 2.3 per 1,000 births based on birthweight ≥500g. The overall PMR was 6.7 deaths per 1,000 births and when corrected for congenital malformation was reduced to 4.4 whereas the respective rates based on birthweight ≥500g were 6.2 and 4.0 per 1,000 births.

Table 1.1: Frequency and rate of perinatal mortality outcomes, 2013

| | BWT ≥500g or delivery ≥24 weeks | | BWT ≥500g | |
|---|---|---|---|---|
| | Number | Rate (95% CI) | Number | Rate (95% CI) |
| Total births | 69,146 | | 69,115 | |
| Stillbirths | 301 | 4.4 (3.9-4.9) | 273 | 3.9 (3.5-4.4) |
| Early neonatal deaths | 162 | 2.4 (2.0-2.7) | 158 | 2.3 (1.9-2.7) |
| Perinatal deaths | 463 | 6.7 (6.1-7.3) | 431 | 6.2 (5.6-6.8) |
| Corrected perinatal deaths | 301 | 4.4 (3.9-4.9) | 274 | 4.0 (3.5-4.4) |

Note: BWT=Birthweight; Rate per 1,000 births; 95% CI=95% confidence interval; Corrected perinatal deaths exclude deaths associated with or due to a congenital malformation.

## International comparison of the rate of stillbirth

The World Health Organization recommends making international comparisons of stillbirth rates based on the criteria of ≥1000g birthweight or ≥28 completed weeks gestation. Adopting these criteria, Figure 1.1 illustrates the Irish stillbirth rate in 2013 compared to the reported stillbirth rate for 23 European countries as detailed in a systematic analysis of worldwide data on stillbirth for 2007-2009.[12] The Irish stillbirth rate was corrected by excluding cases associated with or due to a congenital malformation. As can be seen, Ireland's stillbirth rate is low in the European context.

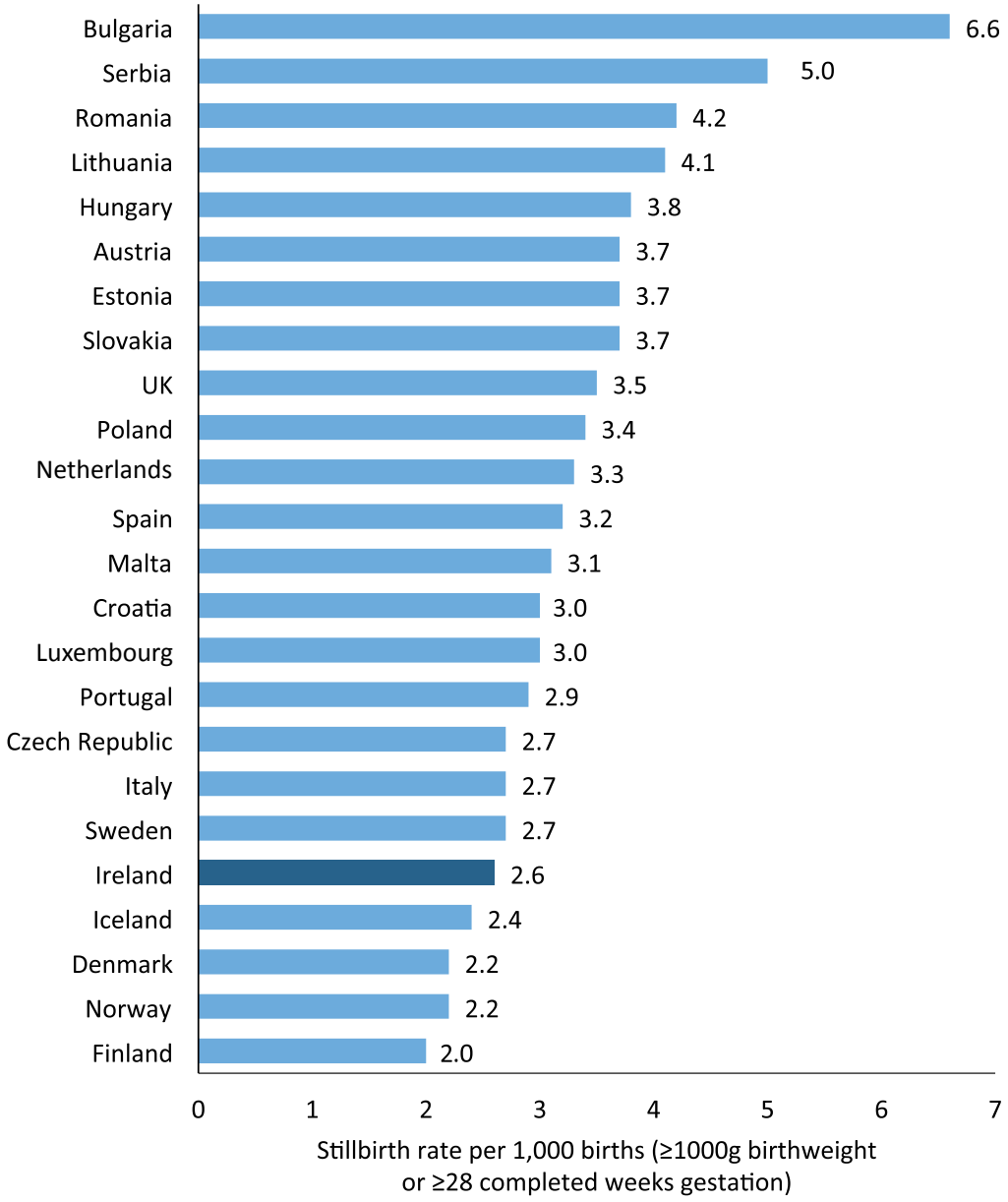



Figure 1.1: Corrected stillbirth rate in Ireland in 2013 compared to stillbirth rate in European countries, 2007-2009

Note: Corrected stillbirth rate excludes cases associated with or due to a congenital malformation; Rates based on stillbirths among births with ≥1000g birthweight or ≥28 completed weeks gestation

12 Cousens S, Blencowe H, Stanton C, Chou D, Ahmed S, Steinhardt L, Creanga AA, Tunçalp O, Balsara ZP, Gupta S, Say L, Lawn JE. National, regional, and worldwide estimates of stillbirth rates in 2009 with trends since 1995: a systematic analysis. Lancet 2011; 377: 1319–30.

## Comparison of perinatal mortality, 2008-2013

Table 1.2 compares the perinatal mortality outcomes for 2013, based on the criteria of birthweight ≥500g or gestation at delivery ≥24 weeks, with those of the previous five years. There are some issues relevant to the comparability of the data. Data were based on 19 maternity units for 2009 and 2010 but were based on all 20 maternity units for other years. Also for 2008-2010, the data for stillbirths were based on birthweights ≥500g whereas for 2011-2013 the data for stillbirths were based on birthweights ≥500g or gestation at delivery ≥24 weeks. As mentioned earlier, the broader criteria leads to the inclusion of relatively more stillbirths than births thereby yielding a higher stillbirth rate. However the stillbirth rate in 2011-2013 (4.2-4.4 per 1,000 births) was lower than in 2008-2010 (4.6-4.8 per 1,000 births).

Respectively, the stillbirth rate, the rate of early neonatal death, the PMR and the corrected PMR were 3%, 19%, 8% and 5% higher in 2013 than in 2012. None of these changes are statistically significant.

Table 1.2: Comparison of perinatal statistics, 2008-2013

| | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 |
|---|---|---|---|---|---|---|
| Total births (N) | 75,421 | 70,250 | 70,182 | 74,265 | 71,755 | 69,146 |
| Total perinatal deaths (N) | 512 | 477 | 463 | 456 | 445 | 463 |
| Stillbirth rate | 4.7 | 4.8 | 4.6 | 4.3 | 4.2 | 4.4 |
| Neonatal death rate | 2.1 | 2.0 | 2.0 | 1.9 | 2.0 | 2.4 |
| Uncorrected PMR (95% CI) | 6.8(6.2-7.4) | 6.8(6.2-7.4) | 6.6(6.0-7.2) | 6.1(5.6-6.7) | 6.2(5.6-6.8) | 6.7(6.1-7.3) |
| Corrected PMR (95% CI) | 4.9(4.4-5.4) | 4.8(4.3-5.3) | 4.5(4.0-5.0) | 4.1(3.6-4.5) | 4.1(3.7-4.6) | 4.4(3.9-4.9) |

Note: 2009-2010 data are based on 19 maternity units whereas others years' data are based on 20 maternity units; Rates per 1,000 births; PMR= perinatal mortality rate; 95% CI=95% confidence interval; Corrected PMR excludes deaths associated with or due to a congenital malformation.

## Variation by maternity unit

Based on birthweights ≥500g or gestation at delivery ≥24 weeks, the uncorrected PMR across the 20 Irish maternity units ranged from 1.6 to 9.3 per 1,000 births (Table 1.3); the corrected PMR ranged from 1.1 to 8.1 per 1,000 births. Thus, there was approximately a sevenfold difference between the lowest and highest PMRs. This level of variation is greater than was observed in the corrected PMR across units in 2011 and 2012.

While there was little change in the corrected PMR between 2012 and 2013 at the national level, there were of course fluctuations at the level of the individual maternity units. There was no correlation between the unit-specific corrected PMR in 2012 and 2013. Indeed, the rate for seven units in 2013 was approximately twice or half the rate for the same unit in 2012, which may be expected when dealing with small numbers in some maternity units.

Table 1.3: Perinatal mortality rates across 20 Irish maternity units in 2012 and 2013

| Unit | Uncorrected PMR (95% CI) | Corrected PMR (95% CI) | |
|---|---|---|---|
| | 2013 | 2013 | 2012 |
| 1 | 9.3 (5.5-13.2) | 8.1 (4.5-11.8) | 5.2 (2.4-7.9) |
| 2 | 8.5 (6.5-10.4) | 5.1 (3.6-6.6) | 5.5 (4.0-7.1) |
| 3 | 8.1 (6.1-10.1) | 5.3 (3.7-6.9) | 4.0 (2.6-5.3) |
| 4 | 7.9 (6.0-9.8) | 5.5 (3.9-7.0) | 3.8 (2.5-5.1) |
| 5 | 7.3 (2.9-11.8) | 4.7 (1.1-8.2) | 5.4 (1.8-8.9) |
| 6 | 6.8 (3.2-10.5) | 4.9 (1.8-8.0) | 2.4 (0.3-4.6) |
| 7 | 6.8 (3.0-10.6) | 3.1 (0.6-5.7) | 3.1 (0.6-5.7) |
| 8 | 6.7 (3.8-9.6) | 4.1 (1.8-6.4) | 3.3 (1.3-5.2) |
| 9 | 6.5 (4.7-8.2) | 3.5 (2.2-4.8) | 3.3 (2.0-4.5) |
| 10 | 6.1 (2.4-9.8) | 2.2 (0.0-4.4) | 2.7 (0.3-5.0) |
| 11 | 6.1 (3.8-8.4) | 4.3 (2.4-6.3) | 4.3 (2.4-6.1) |
| 12 | 5.5 (3.0-7.9) | 4.1 (2.0-6.2) | 4.9 (2.6-7.2) |
| 13 | 5.0 (0.9-9.1) | 5.0 (0.9-9.1) | 2.6 (0.0-5.5) |
| 14 | 4.7 (1.4-8.0) | 2.9 (0.3-5.5) | 7.0 (3.0-11.1) |
| 15 | 4.1 (1.4-6.8) | 2.3 (0.2-4.3) | 3.1 (0.8-5.5) |
| 16 | 4.0 (1.2-6.9) | 4.0 (1.2-6.9) | 2.4 (0.3-4.6) |
| 17 | 4.0 (1.2-6.9) | 2.0 (0.0-4.0) | 3.7 (1.1-6.3) |
| 18 | 3.2 (0.3-6.1) | 1.3 (0.0-3.1) | 4.4 (1.1-7.6) |
| 19 | 2.2 (0.0-4.4) | 1.1 (0.0-2.7) | 6.2 (2.6-9.8) |
| 20 | 1.6 (0.0-3.9) | 1.6 (0.0-3.9) | 3.1 (0.0-6.2) |
| **All** | **6.7 (6.1-7.3)** | **4.4 (3.9-4.9)** | **4.1 (3.7-4.6)** |

Note: Rates per 1,000 births based on birthweights ≥500g or gestation at delivery ≥24 weeks; PMR=perinatal mortality rate; 95% CI=95% confidence interval; Corrected PMR excludes deaths associated with or due to a congenital malformation; Six cases were not included in the rate of a maternity unit as the mother had not received antenatal care from a maternity unit or a self-employed community midwife but presented to a unit after unattended delivery in the community.

The solid horizontal line in Figure 1.2 represents the national corrected PMR in 2013 (4.4 deaths per 1,000 births) and the curved dashed lines represent the 95% confidence interval around the national rate which should include the corrected PMR of individual units. Statistically one in 20 observations can be expected to be outside the 95% confidence range. At 8.1 per 1,000, the corrected PMR of one unit was above the upper limit of the 95% confidence interval indicating that it was statistically significantly higher than the overall rate in 2013. In recent years the rate for this unit was similar to the national rate.

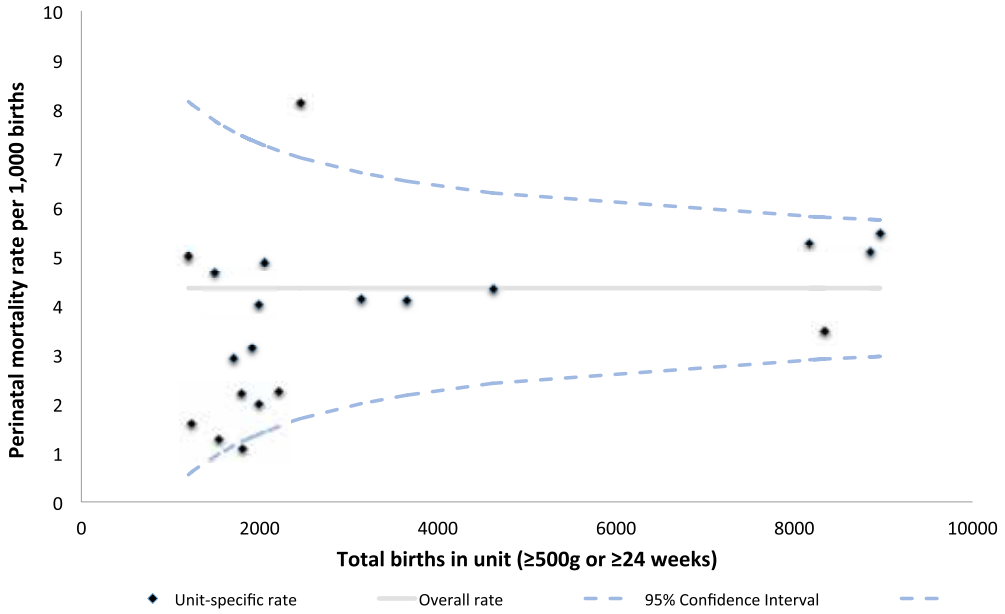



Figure 1.2: Funnel plot of the corrected perinatal mortality rate for Irish maternity units, 2013

In Figure 1.3, the solid horizontal line represents the national stillbirth rate of 4.4 per 1,000. In 19 of the 20 maternity units the stillbirth rate was within the limits of the 95% confidence interval. At 7.7 per 1,000, the stillbirth rate of one unit, the unit that had the outlying corrected PMR, was above the upper limit of the 95% confidence interval indicating that it was statistically significantly higher than the national rate. The rate for this unit was in line with the national rate in recent years.

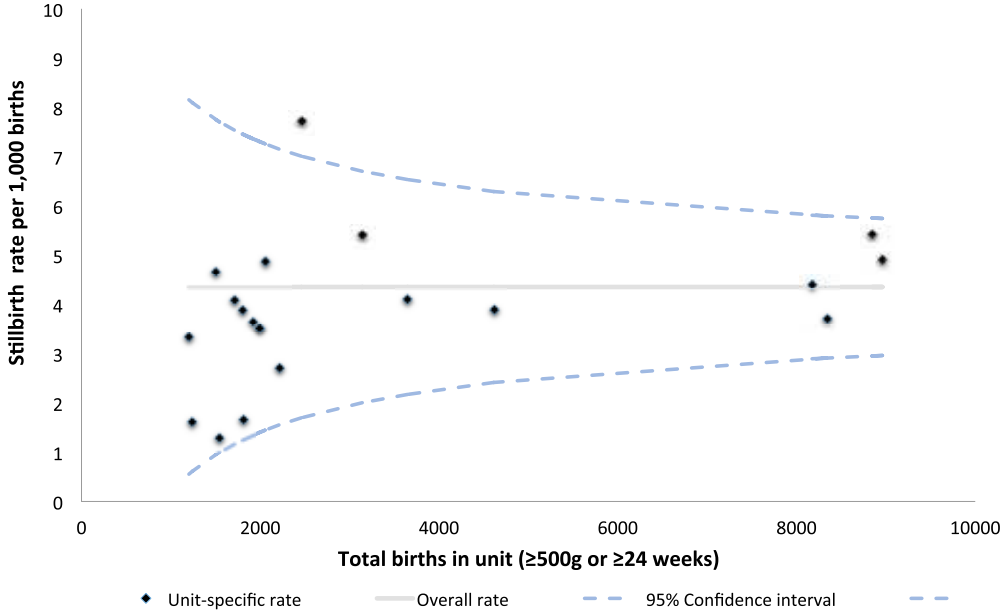



Figure 1.3: Funnel plot of the stillbirth rate for Irish maternity units, 2013

The solid horizontal line in Figure 1.4 represents the overall neonatal mortality rate of 2.4 per 1,000 live births. The neonatal mortality rate from one of the country's large maternity units was above the upper limit of the confidence interval indicating that it was statistically significantly higher than the national rate. However, one third of the early neonatal deaths for this unit followed in utero transfer from another unit, a higher proportion than for any other unit in the country.

In 2011 and 2012 one of the four large maternity unit's had a neonatal mortality rate above the national rate. This finding related to a different unit in each of the three years. Statistically it can be expected for one in 20 observations to be outside the 95% confidence range. The profile of mothers delivered may differ across Irish maternity units and this may explain variation in perinatal mortality rates. However, to establish this requires more detailed information on all mothers delivered at Irish maternity units than is currently available.

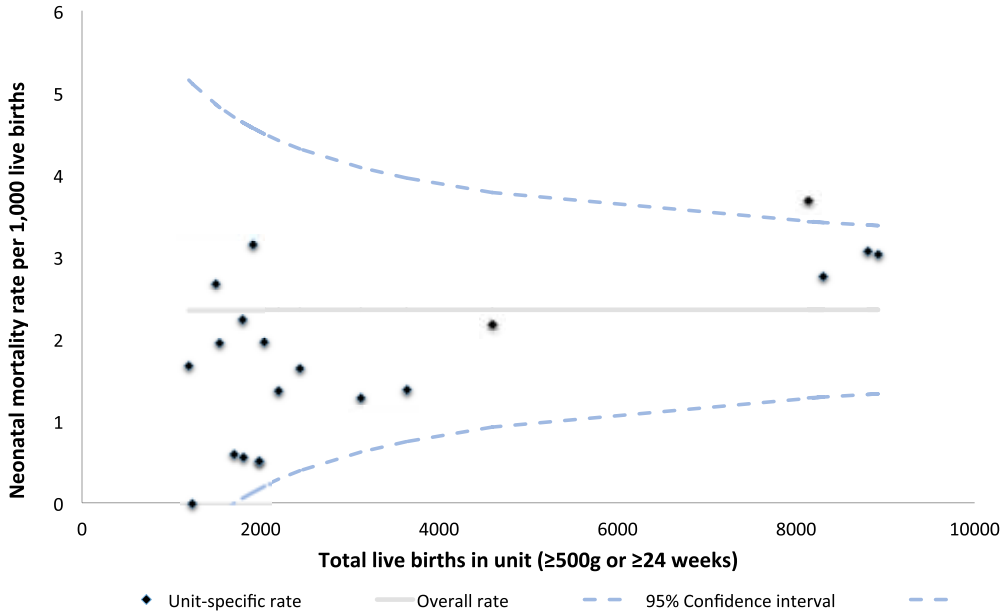



Figure 1.4: Funnel plot of the early neonatal mortality rate for Irish maternity units, 2013

## In utero transfer

In Ireland, women with high risk pregnancies may be transferred to the care of tertiary maternity units with facilities for specialist fetal medicine and high-level neonatal intensive care. Of the 463 perinatal deaths in 2013, there were 51 cases (11.0%) where the care of the pregnant woman was transferred in utero. Of the 445 perinatal deaths in 2012, there were 38 cases (8.5%) where the care of the pregnant woman was transferred in utero.

The 51 in utero transfer cases in 2013 resulted in 17 stillbirths (33.3%) and 34 early neonatal deaths (66.7%). For all but two cases (n=49, 96.1%) the mother was referred to a tertiary maternity unit. Forty-six of the 51 in utero transfer cases were transferred to one of the country's four large maternity hospitals. For these hospitals in 2013, one in six (n=46, 17.3%) of their 220 perinatal deaths arose from in utero transfer cases. This proportion varied across the four hospitals from 7.4% for one hospital, 13.3% for another and for two hospitals almost one in four of their perinatal deaths had been transferred in utero from another unit (22.7% and 23.9%). This shows the impact on perinatal mortality rates for these hospitals associated with in utero transfer.

## Maternal characteristics

The findings presented below are based on stillbirths and early neonatal deaths born with a birthweight ≥500g or gestation at delivery ≥24 weeks.

### Age

The mothers who experienced perinatal loss in 2013 ranged in age from teenage years through to late-forties. Their age distribution broadly reflected that of the population of mothers who gave birth in Ireland (Table 1.4). Close to 60% of the population who gave birth in 2013 were aged 25-34 years whereas mothers who experienced perinatal loss were less often in this age range (48.2%). The age profile of mothers who experienced a stillbirth was similar to that of mothers who experienced early neonatal death.

Table 1.4: Age distribution of mothers experiencing perinatal loss in 2012 and 2013

| Age group | Perinatal deaths (N=440*) 2011 | Perinatal deaths (N=461*) 2013 | All births[13] 2013 | Stillbirths (N=300) 2013 | Neonatal deaths (N=161) 2013 |
|---|---|---|---|---|---|
| <20yrs | 14(3.2) | 10(2.2) | 2.0% | 7(2.3) | 3(1.9) |
| 20-24yrs | 44(10.0) | 53(11.5) | 9.3% | 37(12.3) | 16(9.9) |
| 25-29yrs | 78(17.7) | 82(17.8) | 20.1% | 56(18.7) | 26(16.1) |
| 30-34yrs | 141(32.0) | 140(30.4) | 36.7% | 88(29.3) | 52(32.3) |
| 35-39yrs | 118(26.8) | 136(29.5) | 26.0% | 85(28.3) | 51(31.7) |
| >40yrs | 45(10.2) | 40(8.7) | 5.9% | 27(9.0) | 13(8.1) |

Note: Values are shown as n(%) unless otherwise stated. *Maternal age unknown for five cases in 2012 and two cases in 2013.

13 Healthcare Pricing Office. (2014) *Perinatal Statistics Report 2013*. Dublin: Health Service Executive.

## Ethnicity

Assessment of risk of perinatal loss associated with ethnic group is impeded by the absence of national data on ethnicity for the pregnant population in Ireland. Three-quarters of the mothers who experienced perinatal loss were of white Irish ethnicity. This is close to the proportion of white Irish women in the female population aged 15-49 years enumerated by the National Census 2011. While the numbers involved were small, Irish Traveller, Asian and Black ethnicities were overrepresented in the mothers who experienced perinatal deaths in 2013 as they were in 2012, together accounting for 11% of these mothers compared to 5% of the female 15-49 year-old population.

Table 1.5: Ethnicity of mothers experiencing perinatal loss in 2012 and 2013

| Ethnicity | Perinatal deaths 2012 | Perinatal deaths 2013 | 15-49 year-old female population, 2011 |
|---|---|---|---|
| White Irish | 343(77.1) | 348(75.2) | 80.4% |
| Irish Traveller | 16(3.6) | 12(2.6) | 0.7% |
| Other white background | 49(11.0) | 53(11.4) | 12.5% |
| Asian/Asian Irish | 16(3.6) | 18(3.9) | 2.4% |
| Black/Black Irish | 12(2.7) | 23(5.0) | 1.6% |
| Other/mixed | 6(1.3) | 2(0.4) | 1.0% |
| Not recorded | 3(0.7) | 7(1.5) | 1.4% |

Note: Values are shown as n(%) unless otherwise stated. Population data from the National Census 2011

## Occupation

Lower socio-economic status has been shown to be associated with poor pregnancy outcomes.[14] In the NPEC national clinical audit, data on the mother's and father's occupation at booking was sought. No data were recorded for 64 (13.8%) of the 463 women who experienced perinatal loss down from 17.3% unrecorded occupation for 2012. Table 1.6 provides a high-level overview of the data that were provided on mother's occupation alongside data available for the most comparable categories for mothers of all births from the Perinatal Statistics Report 2013[15] and for the 15-44 year-old female population from the National Census 2011.

An occupation was specified for 64% of the 399 mothers for whom data were recorded (Table 1.6), which is lower than the 70% of all mothers in 2013 with a specified occupation. A limitation of this national audit and data from the Perinatal Statistics Report is that occupation does not assess employment status. It can be seen that unemployed was recorded for 11% of the mothers experiencing perinatal loss compared to 5% of all mothers and 11% of the female population aged 15-44 years. The proportion specified as engaged in home duties was similar for all women who gave birth in 2013 and for those who experienced perinatal loss and was higher than among the general population of women aged 15-44 years.

Table 1.6: Occupation at booking of mothers experiencing perinatal loss, 2013

| Occupation | Perinatal deaths n(%) | All births[16] (%) | 15-44 year-old female population |
|---|---|---|---|
| Occupation specified | 256(64.2) | 70.0 | 55.0%* |
| Unemployed | 44(11.0) | 4.7 | 10.5% |
| Home duties | 86(21.6) | 20.4 | 12.1% |
| Student | 13(3.3) | n/a | 19.9% |
| Others not in labour force | 0(0.0) | n/a | 2.5% |

Note: Population data from Census 2011 relates to economic status rather than occupation, hence * represents the proportion in employment.

14 Centre for Maternal and Child Enquiries (CMACE) (2010) Perinatal Mortality 2008: United Kingdom. London: CMACE
15 Healthcare Pricing Office. (2014) Perinatal Statistics Report 2013. Dublin: Health Service Executive.
16 Healthcare Pricing Office. (2014) Perinatal Statistics Report 2013. Dublin: Health Service Executive.

The NPEC Perinatal Death Notification Form records the highest level of education completed by the mother but this was not provided for the vast majority of the 463 women (338, 73.9%). Level of education is not usually captured in maternity records but has been found to be associated with poor pregnancy outcome.[17]

## Gestation at booking

Gestation at the time of the mother's first antenatal visit to the maternity hospital was unrecorded for 48 cases of perinatal death in 2013 (10.4%). Of those with data, one in five booked into hospital before 12 weeks gestation, almost two-thirds attended for antenatal care between 12 and 19 weeks gestation and 11% attended at 20 weeks gestation or later (Table 1.7).

Table 1.7: Weeks gestation at date of first hospital booking in 2012 and 2013

| Gestation at booking | Perinatal deaths 2012 | Perinatal deaths 2013 | Stillbirths 2013 | Neonatal deaths 2013 |
|---|---|---|---|---|
| Less than 12 Weeks | 104(25.7) | 86(20.7) | 61(21.6) | 25(18.8) |
| 12-19 Weeks | 253(62.5) | 270(65.1) | 185(65.6) | 85(63.9) |
| 20 Weeks or Later | 43(10.6) | 47(11.3) | 27(9.6) | 20(15.0) |
| Not Booked | 5(1.2) | 12(2.9) | 9(3.2) | 3(2.3) |

Note: Values are shown as n(%) unless otherwise stated.

## Fertility treatment

For the first time in 2013, the NPEC Notification Form contained a specific question on whether the pregnancy resulting in perinatal loss was the result of fertility treatment. Information was available for 413 of the 463 cases of perinatal death. In 29 of these cases (7.0%) the pregnancy was reported to be the result of fertility treatment (n=14 of 297 stillbirths, 5.1% and n=15 of 162 early neonatal deaths, 10.6%). Eleven of these 29 pregnancies were associated with multiple births ending in perinatal loss of one or more infants.

The method of treatment was specified for 24 of the 29 pregnancies resulting from fertility treatment. In order of frequency, the methods were: in vitro fertilisation (n=11), clomid (n=7), intracytoplasmic sperm injection (n=2), menopur (n=1) and other (n=3).

17 Savitz, D.A.; Kaufman, J.S.; Dole, N.; Siega-Riz, A.M.; Thorp, J.M., Jr; Kaczor, D.T. Poverty, education, race, and pregnancy outcome. Ethn. Dis. 2004, 14, 322–329.

## Body mass index

Increased maternal BMI has been associated with an increased risk of congenital anomaly and stillbirth.[18,19] The recording of BMI in maternity records is a key recommendation of the Obesity and Pregnancy Clinical Practice National Guideline. While this may be common practice, no national data on the BMI of the pregnant population are available.

Body mass index (BMI) was available for 77.8% (n=360) of women who experienced perinatal loss in 2013, almost identical to the 78.2% rate of recording for 2012. The BMI of 46% of those mothers in 2013 was in the healthy range (18.5-24.9kgm-2) as was the case in 2011 and 2012. In each of the three years, 53% of the mothers who experienced perinatal loss were either overweight or obese albeit with fluctuation in the distribution into these two groups. The pattern of BMI in the mothers who experienced perinatal loss remains similar to that in the women from the general population who participated in the 2007 Survey of Lifestyle, Attitudes and Nutrition (SLÁN).[20]

Table 1.8: Body mass index of mothers who experienced perinatal loss in 2011-2013

| BMI Category ($kgm^{-2}$) | Perinatal deaths 2011 | Perinatal deaths 2012 | Perinatal deaths 2013 | SLÁN 2007 |
|---|---|---|---|---|
| Underweight (<18.5) | 4(1.3) | 2(0.6) | 6(1.7) | 2% |
| Healthy (18.5-24.9) | 140(45.9) | 161(46.3) | 164(45.6) | 44% |
| Overweight (25.0-29.9) | 83(27.2) | 116(33.3) | 98(27.2) | 31% |
| Obese (>30.0) | 78(25.6) | 69(19.8) | 92(25.6) | 23% |

Note: Values are shown as n(%) unless otherwise stated; SLÁN, Survey of Lifestyle, Attitudes and Nutrition

## Smoking and substance abuse

Smoking status of the mothers at their time of booking was recorded for 421 (90.9%) of the 463 women. Of these, 75 (17.8%) were smokers at the time – similar to the 17.2% prevalence reported for 2012. Most were smoking at least 10 cigarettes per day (n=41 of 71, 57.7%; quantity unknown for four cases). Information on smoking in late pregnancy was available for 44 of the 75 smokers (58.7%); eight (18.2%) stopped smoking during pregnancy.

The prevalence of smoking during pregnancy or in the last trimester is not routinely known for all Irish pregnancies but rates of 12%, 15%, 16% and 19% have been reported for England, Northern Ireland, Wales and Scotland, respectively.[21]

There were four cases with a documented history of alcohol abuse and seven women had a documented history of drug abuse.

18 Rasmussen SA, Chu SY, Kim SY, Schmid CH, Lau J. Maternal obesity and risk of neural tube defects: a metaanalysis. Am J Obstet Gynecol 2008;198:611-9
19 Chu SY, Kim SY, Lau J, Schmid CH, Dietz PM, Callaghan WM, et al. Maternal obesity and risk of stillbirth: a metaanalysis. Am J Obstet Gynecol 2007;197:223-8.
20 Harrington J, Perry IJ, Lutomski J, Morgan K, McGee H, Shelley E, Watson D. (2008) Survey of Lifestyle, Attitudes and Nutrition in Ireland: Dietary Habits of the Irish Population. Dublin: The Stationery Office.
21 EURO-PERISTAT Project with SCPE and EUROCAT. European Perinatal Health Report. The health and care of pregnant women and babies in Europe in 2010. May 2013. Available www.europeristat.com

## Previous pregnancy

Over two thirds of the mothers who experienced perinatal loss in 2013 had at least one previous pregnancy (326 of 463, 70.4%).

In terms of parity, women who experienced perinatal loss were similar to the population of women who gave birth in 2013. However, as in previous years, (Table 1.9) they were more likely to be Para+ 3 compared to the general population of women delivered.

Table 1.9: Distribution of parity, 2011-2013

| Parity | Perinatal deaths 2011 | Perinatal deaths 2012 | Perinatal deaths 2013 | All births[22] 2013 |
|---|---|---|---|---|
| Nulliparous | 205(45.5) | 186(41.8) | 174(37.6) | 38.5% |
| Para 1 | 122(27.1) | 129(29.0) | 137(29.6) | 35.1% |
| Para 2 | 71(15.7) | 72(16.2) | 87(18.8) | 17.3% |
| Para 3+ | 53(11.7) | 58(13.0) | 65(14.0) | 9.1% |

Note: Values are shown as n(%) unless otherwise stated.

Table 1.10 specifies gravida/parity for the 460 women who experienced perinatal loss in 2013 (gravida/parity was unknown for three women with a previous pregnancy). Thirty percent (n=137, 29.8%) had never been pregnant before (gravida = 0). Of the 323 women who had been pregnant (gravida > 0), most (n=181, 56.0%) only had pregnancies exceeding 24 weeks or 500g birthweight (gravida = parity, indicated by green shading); one in three (n=105, 32.5%) experienced at least one pregnancy exceeding 24 weeks or 500g birthweight and at least one pregnancy less than 24 weeks gestation and under 500g birthweight (gravida > parity > 0, indicated by yellow shading); and, for 11.5% (n=37) their previous pregnancies never exceeded 24 weeks gestation or 500g birthweight (gravida > parity = 0, indicated by orange shading).

Table 1.10: Gravida/parity of mothers prior to experiencing perinatal loss in 2013

| Gravida \ Parity | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 13 | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 137 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 137 |
| 1 | 23 | 93 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 116 |
| 2 | 12 | 26 | 50 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 88 |
| 3 | 2 | 12 | 26 | 25 | 0 | 0 | 0 | 0 | 0 | 0 | 65 |
| 4 | 0 | 2 | 6 | 8 | 8 | 0 | 0 | 0 | 0 | 0 | 24 |
| 5 | 0 | 1 | 3 | 4 | 1 | 3 | 0 | 0 | 0 | 0 | 12 |
| 6 | 0 | 0 | 1 | 0 | 1 | 3 | 1 | 0 | 0 | 0 | 6 |
| 7 | 0 | 0 | 0 | 3 | 0 | 1 | 0 | 0 | 0 | 0 | 4 |
| 8 | 0 | 0 | 0 | 1 | 0 | 0 | 1 | 1 | 0 | 0 | 3 |
| 9 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 |
| 10 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| 11 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 12 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 |
| 13 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 |
| 14 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 15 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 |
| Total | 174 | 134 | 87 | 41 | 10 | 7 | 2 | 3 | 1 | 1 | 460 |

Note: We refer to gravida and parity prior to the pregnancy followed by perinatal death in 2013. Green represents women with previous pregnancies always ≥24 weeks or ≥500g; yellow represents women who had experienced pregnancy ≥24 weeks or ≥500g and pregnancy <24 weeks and <500g; and, orange represents women whose previous pregnancies were always <24 weeks gestation and <500g birthweight.

22 Healthcare Pricing Office. (2014) Perinatal Statistics Report 2013. Dublin: Health Service Executive.

Of the 326 women who had a previous pregnancy, 40% (n=130, 39.9%) were reported to have had a previous pregnancy-related problem (Table 1.11). Almost one in five of the 326 mothers had a previous caesarean delivery. Three or more miscarriages, pre-term birth or mid-trimester loss and pre-eclampsia were each experienced by 4% of the mothers who had a previous pregnancy.

Table 1.11: Previous pregnancy-related problems in mothers who experienced perinatal loss in 2011-2013

| | 2011 n(%) | 2012 n(%) | 2013 n(%) |
|---|---|---|---|
| Previous caesarean delivery | 55(18.9) | 60(19.9) | 61(18.7) |
| Three or more miscarriages | 19(6.5) | 13(4.3) | 14(4.3) |
| Pre-term birth or mid-trimester loss | 11(3.8) | 13(4.3) | 14(4.3) |
| Pre-eclampsia | 18(6.2) | 19(6.3) | 13(4.0) |
| Baby with congenital anomaly | 7(2.4) | 9(3.0) | 10(3.1) |
| Stillbirth | 5(1.7) | 11(3.7) | 9(2.8) |
| Neonatal death | 7(2.4) | 3(1.0) | 5(1.5) |
| Infant requiring intensive care | 8(2.7) | 6(2.0) | 4(1.2) |
| Post-partum haemorrhage requiring transfusion | 5(1.7) | 6(2.0) | 3(0.9) |
| Placental abruption | 2(0.7) | 4(1.3) | 1(0.3) |
| Placenta praevia | 1(0.3) | 1(0.3) | 1(0.3) |
| Other | 68(23.4) | 54(17.9) | 39(12.0) |

Note: Percentage of mothers who had a previous pregnancy

## Pre-existing medical conditions

Information about pre-existing medical problems was available for 440 of the 463 mothers who experienced perinatal loss (95.0%). One in three of these 440 women had a pre-existing medical problem (146, 33.2%). This is lower than the 40% rate in 2012 and the 45% rate in 2011. There were no highly prevalent conditions and no notable changes in the prevalence of specific problems from 2011 to 2013 (Table 1.12). The Other category included a wide range of problems such as asthma, anaemia, infertility and urinary tract infection.

Table 1.12: Pre-existing medical conditions in mothers who experienced perinatal loss in 2011-2013

| | 2011 n(%) | 2012 n(%) | 2013 n(%) |
|---|---|---|---|
| Psychiatric disorder | 23(5.7) | 19(4.5) | 25(5.7) |
| Endocrine disorder | 19(4.7) | 21(5.0) | 17(3.9) |
| Diabetes | 7(1.7) | 8(1.9) | 13(3.0) |
| Cardiac disease | 8(2.0) | 6(1.4) | 11(2.5) |
| Hypertension | 12(3.0) | 22(5.2) | 7(1.6) |
| Renal disease | 7(1.7) | 9(2.1) | 6(1.4) |
| Epilepsy | 7(1.7) | 5(1.2) | 4(0.9) |
| Inflammatory disorder | 7(1.7) | 7(1.7) | 3(0.7) |
| Haematological disorder | 7(1.7) | 6(1.4) | 3(0.7) |
| Other | 126(31.3) | 103(24.3) | 92(20.9) |
| Any pre-existing medical problem | 179(44.5) | 169(40.0) | 146(33.2) |

## Delivery

Labour was induced in 60.8% of women who experienced a stillbirth (n=183 of 301) and 13.7% of those who experienced a neonatal death (n=22 of 161; unknown for one case). A caesarean section was the planned mode of delivery for 8.4% of the women who experienced a stillbirth (n=25 of 297; unknown for four cases) and 25.3% of the women who experienced an early neonatal death (n=41 of 162).

Approximately 95% of the babies (n=444 of 463, 95.9%) were delivered under obstetric-led care which is the predominant model of care in Ireland. Six babies (1.3%) were delivered under midwifery-led care and 13 babies (2.8%) were born before arrival at the maternity unit (seven stillbirths and six early neonatal deaths).

Presentation at delivery, known for 439 of the 463 babies, was vertex presentation for 73.8% (n=324), one in four was breech presentation (n=107, 24.4%) and in eight cases the presentation was either compound (n=5) or face (n=3).

Spontaneous vaginal was the mode of delivery for approximately two thirds of stillbirths and for almost 40% of the babies who died in the early neonatal period (Table 1.13). Almost half of the deliveries in cases of neonatal death involved caesarean section (47.5%), usually pre-labour. One in eight cases of stillbirth involved caesarean section again predominantly pre-labour. Among stillbirths delivered by caesarean section, one third of the mothers (n=13 of 39, 33.3%) had had a previous caesarean delivery. Assisted breech deliveries were relatively common in cases of stillbirth (16.6%) and neonatal death (11.1%) whereas this was a very rare mode of delivery for all births in 2013.

Table 1.13: Mode of delivery for mothers who experienced perinatal loss in 2013

| Mode of delivery | Stillbirths (N=301) | Neonatal deaths (N=162) | All births[23] % |
|---|---|---|---|
| Spontaneous vaginal delivery | 209(69.4) | 63(38.9) | 55.2% |
| Pre-labour caesarean section | 29(9.6) | 51(31.5) | 29.7% |
| Caesarean section after onset of labour | 10(3.3) | 26(16.0) | |
| Lift out forceps | 1(0.3) | 2(1.2) | 3.8% |
| Mid-cavity forceps | 1(0.3) | 1(0.6) | |
| Rotational forceps | - | - | |
| Assisted breech | 50(16.6) | 18(11.1) | 0.4% |
| Ventouse | 1(0.3) | 1(0.6) | 10.8% |

Note: Values are n(%) unless otherwise stated.

Emergency caesarean section delivery was the most common type, accounting for 45.2% of the 116 cases of perinatal death delivered by caesarean section (n=52, unknown for one case), over 20% were categorised as urgent (n=26, 22.6%) and one in three were elective (n=37, 32.2%). The type of caesarean delivery did not differ in this regard between cases of stillbirth and early neonatal death.

23 Healthcare Pricing Office. (2014) Perinatal Statistics Report 2013. Dublin: Health Service Executive.

### Level of care for mothers post-delivery

For women who experienced perinatal loss in 2013, 6.4% were admitted into a high dependency unit (HDU) and 1.3% were admitted into an intensive care unit (ICU). Similar admission rates were reported for 2011 and 2012 (Table 1.14). Admission to the HDU for the mother was more common in cases of early neonatal death than stillbirth whereas all six ICU admissions occurred following stillbirth. Deliveries by emergency caesarean section were associated with the highest rates of admission to both the HDU (n=13 of 52, 25.0%) and ICU (n=4 of 52, 7.7%).

Table 1.14: Post-delivery outcome for mothers who experienced perinatal loss in 2011-2013

| | Perinatal deaths 2011 | Perinatal deaths 2012 | Perinatal deaths 2013 | Stillbirths 2013 | Neonatal deaths 2013 |
|---|---|---|---|---|---|
| Admitted to HDU | 27(5.9) | 29(6.5) | 29(6.4) | 11(3.7) | 18(11.2) |
| Admitted to ICU | 8(1.8) | 7(1.6) | 6(1.3) | 6(2.0) | 0(0.0) |

Note: Values are n(%) unless otherwise stated. Admission data unknown for seven women in 2013.

## Infant characteristics

The findings presented below are based on stillbirths and early neonatal deaths born with a birthweight ≥500g or gestation at delivery ≥24 weeks.

### Sex

There were five perinatal deaths for which the sex of the baby was indeterminate (sex was unreported for one case of stillbirth). Of the 457 other perinatal deaths, 56% were male (n=255, 55.8%). In the overall population of births in 2013, 51.3% were male.[24] Male babies significantly outnumbered female babies among early neonatal deaths but only marginally so among stillbirths (Table 1.15).

Table 1.15: Sex of baby in stillbirths and neonatal deaths in 2013

| | Stillbirths n(%) | Early neonatal deaths n(%) |
|---|---|---|
| Male | 155(51.7) | 100(61.7) |
| Female | 141(47.0) | 61(37.7) |
| Indeterminate | 4(1.3) | 1(0.6) |

Note: Sex was not reported for one case of stillbirth.

### Multiple births

There was an association between perinatal death and multiple pregnancies. There were 46 perinatal deaths from multiple births, making up 9.9% of all perinatal deaths in 2013. This is nearly three times the proportion of multiples among all births in 2013 (3.8%).[25] Consequently, the perinatal mortality rate of 17.6 per 1,000 multiple births was nearly three times the national perinatal mortality rate for all babies.

The 46 perinatal deaths from multiple births comprised 20 stillbirths and 26 early neonatal deaths. Most (n=17, 65.4%) of the 26 early neonatal deaths from multiple births were due to respiratory disorders, most often severe pulmonary immaturity and generally associated with spontaneous premature labour. The main causes of the 20 stillbirths from multiple births were twin-twin transfusion (n=6, 30.0%) and specific placental conditions (n=6, 30.0%) while the main cause was unexplained for four cases (20.0%).

Chorionicity was reported for 39 of the 46 perinatal deaths from multiple births. There was a small excess of cases that were

24 Healthcare Pricing Office. (2014) Perinatal Statistics Report 2013. Dublin: Health Service Executive.
25 Healthcare Pricing Office. (2014) Perinatal Statistics Report 2013. Dublin: Health Service Executive.

monochorionic diamniotic (n=20, 51.3%) compared to dichorionic diamniotic (n=18, 46.2%) and one case was monochorionic monoamniotic. The observed proportion of monochorionic diamniotic twins is higher than would be expected based on all twin deliveries in Ireland.

There were 27 cases where one twin died, eight cases where both twins died and three cases where one triplet died indicating a total of 38 pregnancies. It was reported that 11 of these pregnancies were a result of fertility treatment (information unknown for six pregnancies).

## Gestation

More than two thirds of perinatal deaths in 2013 were associated with delivery before 37 weeks gestation (n=323 of 459, 70.4%; gestation at delivery unknown for four cases). This was the case for 68.5% of stillbirths (n=204 of 298; unknown for three cases) and 73.9% of early neonatal deaths (n=119 of 161; unknown for one case). Extremely pre-term delivery, i.e. delivery at 22-27 weeks gestation, was more often associated with cases of early neonatal death than cases of stillbirth (Figure 1.5).

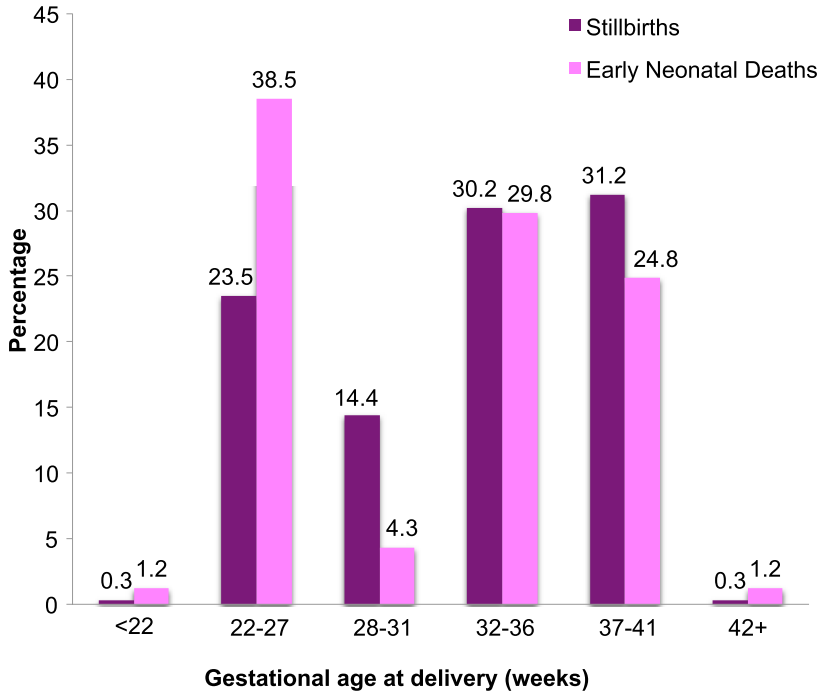



Figure 1.5: Distribution of gestational age at delivery in stillbirths and neonatal deaths in 2013

## Birthweight

The most represented birthweight in cases of perinatal death was in the range 500-999 grams (n=117 of 462, 25.3%; birthweight unknown for one case). This was more so for early neonatal deaths than stillbirths (Figure 1.6). For almost three quarters of perinatal deaths (n=332, 71.9%; n=209, 69.4% of stillbirths; n=123, 76.4% of neonatal deaths) the birthweight was less than 2,500 grams.

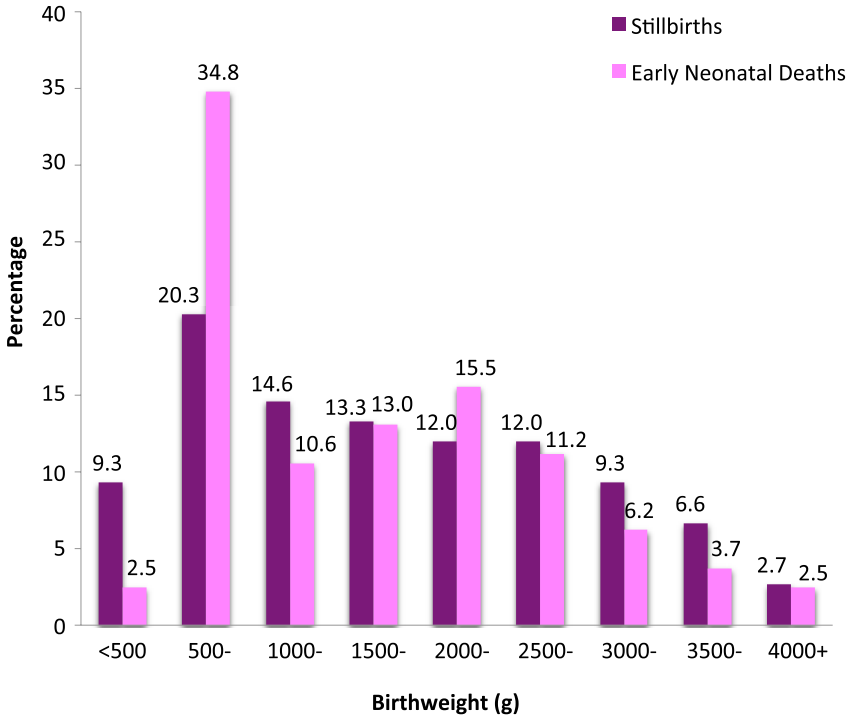



Figure 1.6: Distribution of birthweight in stillbirths and neonatal deaths in 2013

## Birthweight centile

An increased risk of perinatal death has been associated with failure of fetal growth in utero. We have produced two charts to highlight this issue in relation to the stillbirths and early neonatal deaths that occurred in Ireland in 2013. To do so, we used the Gestation Related Optimal Weight (GROW) software[26] and coefficients derived from the multiple regression analysis of data on 11,072 births in six maternity units in Dublin, Galway, Limerick and Belfast in 2008-2009. [27]

The regression analysis determined the Term (i.e. 40 weeks) Optimal Weight (TOW) in Ireland to be 3,490.7g. The normal range (i.e. the range from the 10th centile weight to the 90th centile weight) around the TOW was then calculated and the recommended proportionality growth function was applied to the TOW, the 10th centile term weight and the 90th centile term weight in order to determine the optimal weight and normal range at all gestations (21-44 weeks for the stillbirths and early neonatal deaths in Ireland in 2013). These steps are described in detail in the GROW documentation.

The optimal weight and normal range for all gestations are plotted with the actual birthweights of the stillbirths in Figure 1.7 and with the birthweights for cases of early neonatal death in Figure 1.8. For the stillbirths, it can be seen that a high proportion were below the lower limit of the normal range (10th centile). In cases of early neonatal death, the birthweight was often below the normal range, particularly for births after 33 weeks gestation. However, low birthweight was observed less often than for cases of stillbirth.

Figures 1.7 and 1.8 have the limitation of plotting actual birthweights against the optimal weight and normal range adjusted only for gestational age. There is no adjustment for other factors affecting birthweight, namely, maternal height, weight, parity and ethnic group and infant sex. The use of centiles customised for maternal and infant characteristics affecting birthweight identifies small babies at higher risk of mortality better than population centiles.[28] Small-for-gestational-age (SGA) refers to birthweights below the 10th centile and severely SGA refers to birthweights less than the 3rd centile.[29]

26 Gardosi J, Francis A. Customised Weight Centile Calculator. GROW version 6.7.6.5(IE), 2015 Gestation Network, www.gestation.net
27 Unterscheider J, Geary MP, Daly S, McAuliffe FM, Kennelly MM, Dornan J, Morrison JJ, Burke G, Francis A, Gardosi J, Malone FD. The customized fetal growth potential: a standard for Ireland. Eur J Obstet Gynecol Reprod Biol 2013; 166(1):14-7
28 Clausson B, Gardosi J, Francis A, Cnattingius S. Perinatal outcome in SGA births defined by customised versus population–based birthweight standards. BJOG 2001;108:830–4.
29 Royal College of Obstetrics and Gynaecologists. The investigation and management of the small-for-gestational age fetus. RCOG Green Top Guideline 2013 (NO.31). Available at: www.rcog.org.uk/files/rcog-corp/22.3.13GTG31SGA_ExecSum.pdf

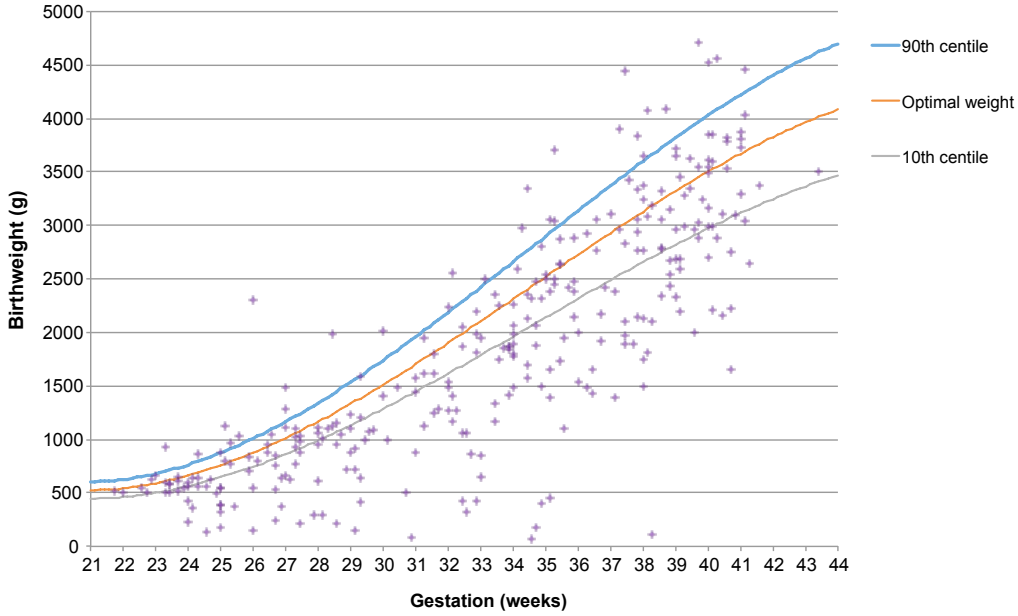



Figure 1.7: Optimal birthweight and normal range compared to actual birthweights of stillbirths, 2013

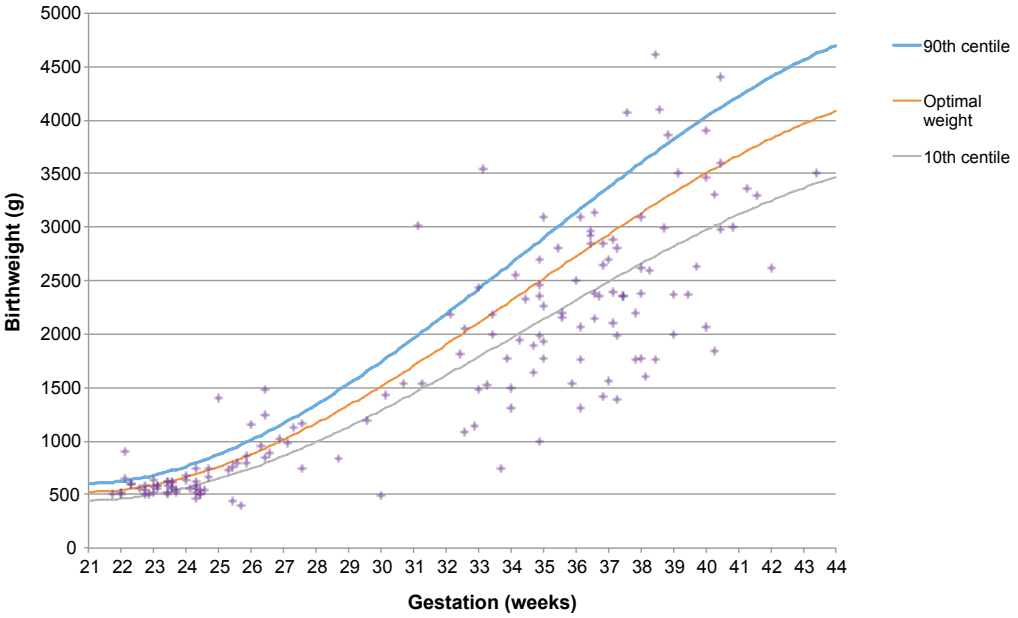



Figure 1.8: Optimal birthweight and normal range compared to actual birthweights in cases of early neonatal death, 2013

Customised birthweight centiles were derived using the GROW software.[30] There was a high level of missing data for maternal height and weight with one or both unknown for 27.0% of the mothers (n=125). For these cases, we used the median height and weight of the mothers with complete data. The GROW software also provides estimated customised birthweight centiles in cases with missing data. Ultimately, customised birthweight centiles were calculated for 459 of the 463 mothers (99.1%).

The distribution of customised birthweight centiles at all gestations is illustrated for stillbirths in Figure 1.9 and for cases of early neonatal death in Figure 1.10. At all gestations, there were cases spanning the full range of birthweight centiles (i.e. 0-100th) but there was a clear overrepresentation of cases below the median and far more at or near centile zero than would be expected in the population of all births.

30 Gardosi J, Francis A. Customised Weight Centile Calculator. GROW version 6.7.6.5(IE), 2015 Gestation Network, www.gestation.net

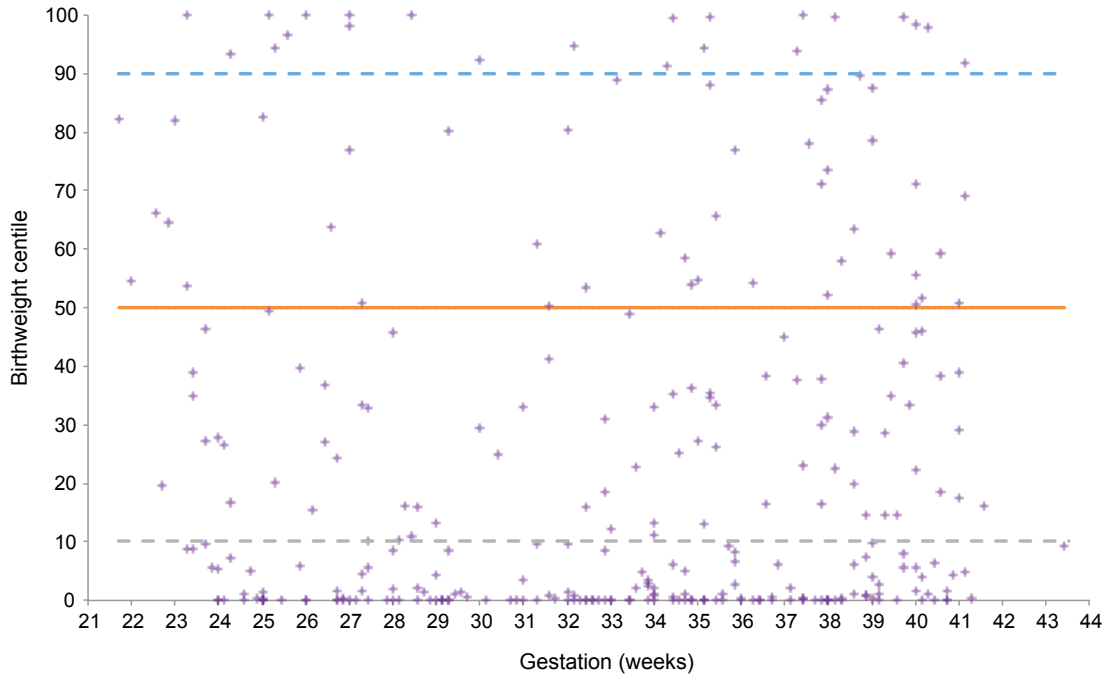



Figure 1.9: Distribution of customised birthweight centiles for stillbirths, 2013

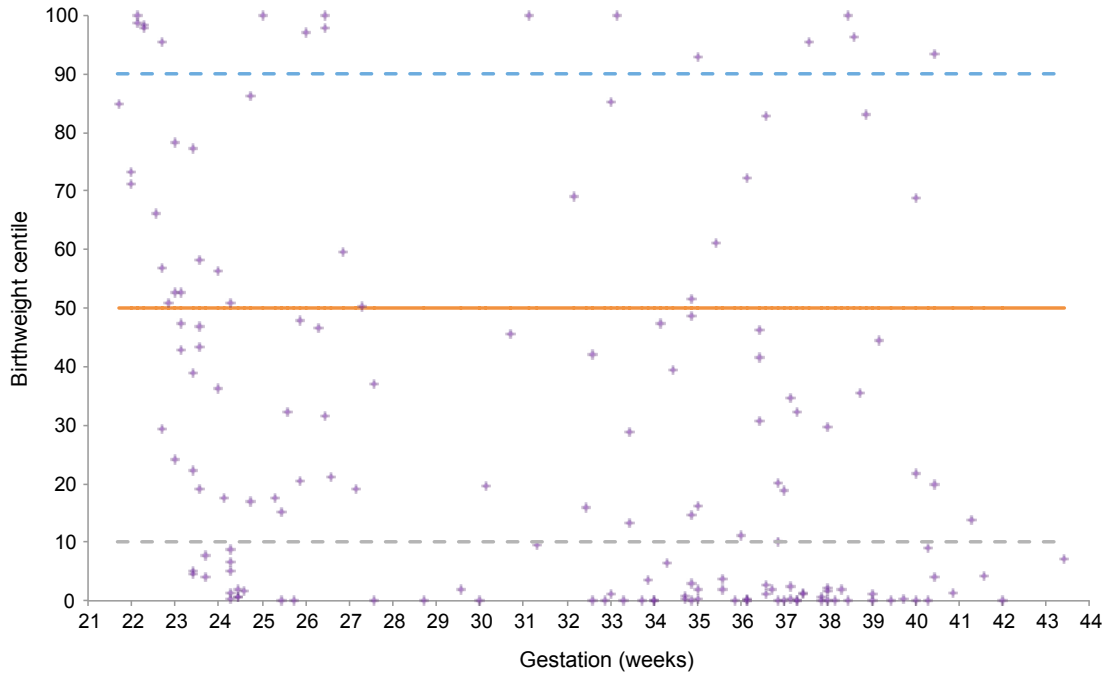



Figure 1.10: Distribution of customised birthweight centiles for early neonatal deaths, 2013

Table 1.16 details the number and percentage of stillbirths and early neonatal deaths within specific ranges of customised birthweight centiles. Low birthweight was associated with both groups but particularly with stillbirths. Thirty percent had a birthweight at centile zero compared to 21% of early neonatal death cases. Forty percent of stillbirths were classified as severely SGA and over half were SGA compared to 35% and 45% of the cases of early neonatal death, respectively.

SGA may be more prevalent among stillborn babies because they may have died some days or weeks before being delivered. We do not record whether there was evidence of maceration in cases of stillbirth but there was support for this hypothesis. The data showed a correlation whereby the longer the time between confirmation of death and time of delivery, the lower the customised birthweight centile of the stillborn baby.

Table 1.16: Distribution of customised birthweight centiles, 2013

| Centile | Stillbirth n(%) (N=298) | Neonatal death n(%) (N=160) |
|---|---|---|
| Zero | 88(29.5) | 34(21.1) |
| < 3rd | 120(40.3) | 57(35.4) |
| < 10th | 158(53.0) | 72(44.7) |
| 10-49th | 75(25.2) | 48(29.8) |
| 50-89th | 43(14.4) | 24(14.9) |
| 90th+ | 22(7.4) | 17(10.6) |

Note: Centiles could not be calculated for three stillbirths and one early neonatal death; Values are n(%).

Cases of stillbirth and early neonatal death were at significantly lower birthweight centiles when the cause of death was attributed to major congenital anomaly (Table 1.17). Most of the 69 stillbirths due to congenital anomaly (n=41, 59.4%) were severely SGA (<3rd customised birthweight centile) whereas this was the case for one third of the stillbirths due to other causes (n=79, 34.5%). Similarly, half of the 92 early neonatal deaths due to congenital anomaly (n=46) were severely SGA compared to 16% (n=11) of the 69 early neonatal deaths due to other causes.

Table 1.17: Distribution of customised birthweight centiles of perinatal deaths due and not due to major congenital anomaly, 2013

| Centile | Stillbirth (N=298) | | Neonatal death (N=161) | |
|---|---|---|---|---|
| | Cause of death: major congenital anomaly | | Cause of death: major congenital anomaly | |
| | Yes (n=78) | No (n=220) | Yes (n=68) | No (n=72) |
| Zero | 35(50.7%) | 53(23.1%) | 30(32.6%) | 4(5.8%) |
| < 3rd | 41(59.4%) | 79(34.5%) | 46(50.0%) | 11(15.9%) |
| < 10th | 49(71.0%) | 109(47.6%) | 54(58.7%) | 18(26.1%) |
| 10-49th | 9(13.0%) | 66(28.8%) | 21(22.8%) | 27(39.1%) |
| 50-89th | 1(1.4%) | 42(18.3%) | 8(8.7%) | 16(23.2%) |
| 90th+ | 10(14.5%) | 12(5.2%) | 9(9.8%) | 8(11.6%) |

Note: Centiles could not be calculated for three stillbirths and one early neonatal death

## Diagnosis of intra-uterine growth restriction (IUGR)

The NPEC Perinatal Death Notification Form contains a specific question on whether a diagnosis of IUGR was made in perinatal deaths and the timing of diagnosis if applicable. A diagnosis of IUGR was reported for 76 (16.6%) of the 463 perinatal deaths (unknown for four cases) - 17.8% of stillbirths (n=53) and 14.2% of early neonatal deaths (n=23). In most diagnosed cases, IUGR was suspected antenatally (Table 1.18). Approximately 80% of the cases with a diagnosis of IUGR (n=62 of 76, 81.6%) were severely SGA (<3rd customised birthweight centile). Major congenital anomaly was the main cause of death in almost half of the cases with a diagnosis of IUGR (n=36, 47.4%), placental conditions were the main or associated cause of death in one in four cases (n=17, 22.4%) and IUGR was the main or associated cause of death for five cases (6.5%).

Table 1.18: Diagnosis of intra-uterine growth restriction, 2013

| | Stillbirth n(%) (N=53) | Neonatal death n(%) (N=23) |
|---|---|---|
| Suspected antenatally | 34(64.2) | 21(91.3) |
| Observed at delivery | 36(67.9) | 14(60.9) |
| Observed at post-mortem | 17(32.1) | 1(4.3) |

Note: Categories are not mutually exclusive and may add up to more than 100%

Among the 421 mothers whose smoking status was known at the time of their hospital booking, there was little difference in the prevalence of diagnosed IUGR in the infants of smokers (n=10 of 75, 13.3%) and non-smokers (n=62 of 346, 17.9%). A diagnosis of IUGR was relatively common among mothers with a pregnancy-related hypertensive disorder (n=11 of 27, 40.7% versus n=65 of 432 mothers without pregnancy-related hypertension, 15.0%).

## Investigations to determine the cause of death

### Autopsy

Current practice guidelines[31] recommend that parents should be offered a full post-mortem examination of the stillborn infant to help explain the cause of death. Data on autopsy uptake was reported for 456 of the 463 perinatal deaths of which 45.4% (n=207) underwent an autopsy. This rate of autopsy uptake is identical to the 45.2% rate in 2012 and higher than in 2011 when 40.7% of perinatal deaths had an autopsy performed. The trend in the perinatal autopsy rate is illustrated in Figure 1.11. A decline in the rate of autopsy was observed in 2008-2011. The rate is always higher for stillbirths than in cases of early neonatal death albeit by a smaller margin in recent years.

In Ireland in 2013, an autopsy was undertaken following 48.5% of stillbirths (n=144 of 297, unknown for four cases) and 39.6% of early neonatal deaths (n=63 of 159, unknown for three cases). These rates are higher than in the UK as a whole in 2013 (full autopsy for 44.7% of stillbirths and 29.6% of early neonatal deaths)[32] whereas the autopsy rate in Northern Ireland in 2013 was higher for stillbirths (60%) and similar for early neonatal deaths (41%).[33]

31 Clinical Practice Guideline No 4 (2011). Investigation and management of late fetal intrauterine death and stillbirth: Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Strategy and Clinical Programmes, Health Service Executive.
32 Manktelow BM, Smith LK, Evans TA, Hyman-Taylor P, Kurinczuk JJ, Field DJ, Smith PW, Draper ES, on behalf of the MBRRACE-UK collaboration. Perinatal Mortality Surveillance Report UK Perinatal Deaths for births from January to December 2013. Leicester: The Infant Mortality and Morbidity Group, Department of Health Sciences, University of Leicester. 2015.
33 Northern Ireland Maternal and Child Health. (2015) Perinatal mortality: Northern Ireland 2013. Belfast: Northern Ireland Public Health Agency.

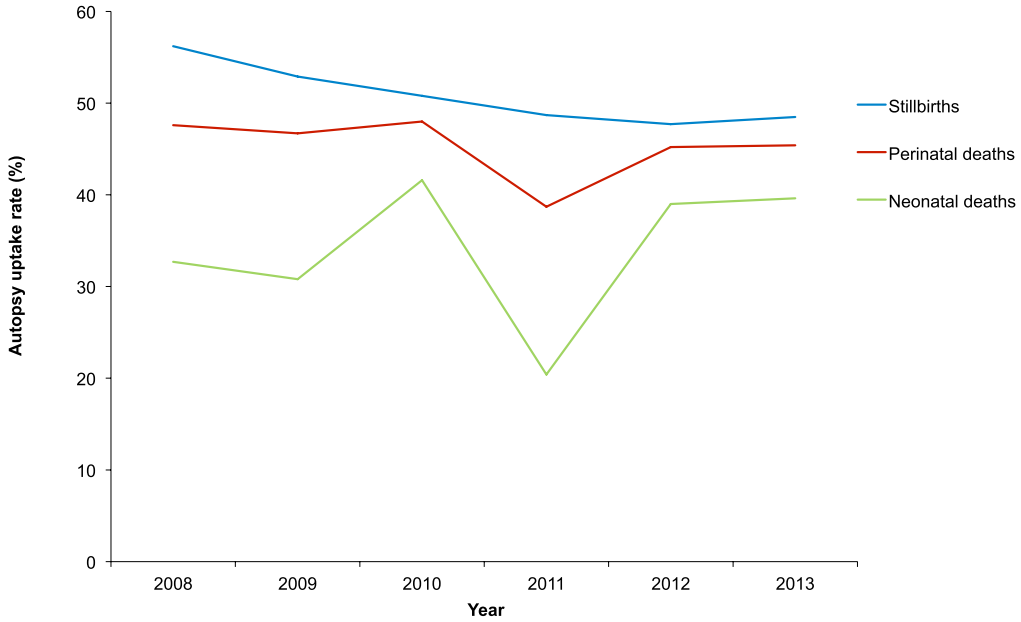



Figure 1.11: Autopsy uptake rate, 2008-2013

There was significant variation in the rate of autopsy across the 20 maternity units in 2013 as illustrated in Figure 1.12. Most of this variation was observed across the smaller maternity units as the autopsy rate for the four large maternity units was 47.0-61.1%. To some extent this is a consequence of the small numbers of perinatal deaths involved but it may also reflect variation in access to dedicated perinatal pathology services for smaller units – a common communication to the NPEC from smaller units. The autopsy rate in each of the four large maternity units was above the national rate.

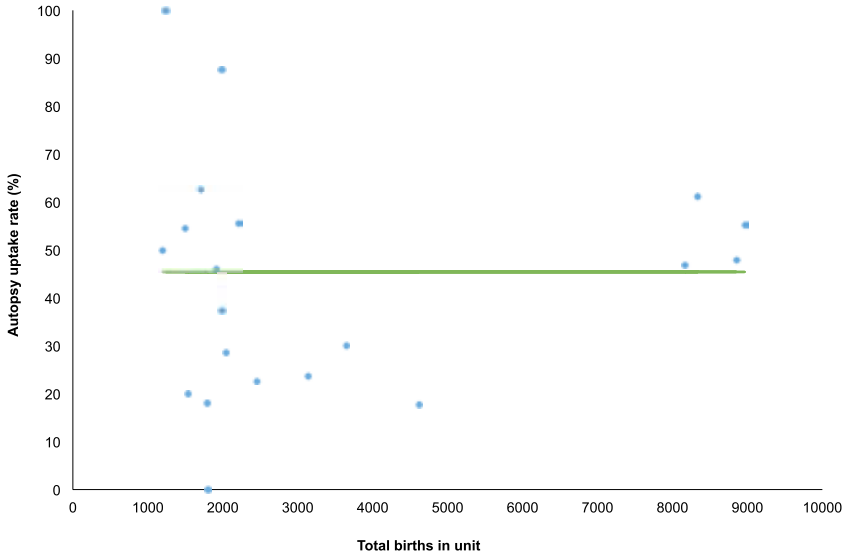



Figure 1.12: Autopsy uptake in the 20 Irish maternity units in 2013

Figure 1.13 details the autopsy-related steps taken following 456 of the 463 perinatal deaths in 2013. Thirty-one of the deaths (6.8%) became coroner cases. These cases underwent autopsy and at the time data were reported to the NPEC, the maternity unit had received the autopsy report from the coroner's office in 25 of the 31 cases (80.6%). There were 176 autopsies undertaken following the 425 deaths that were not coroner cases, an autopsy rate of 41.4% (129, 43.4% for stillbirths and 47, 29.6% for early neonatal deaths).

There were 249 perinatal deaths that did not receive an autopsy. For the majority of these cases an autopsy was offered and presumably declined by parents (n=208, 83.9%, unknown for one case). This is an increase in the rate of autopsy offer from 78.0% for 2012. Such an offer was made more often in cases of stillbirth (137 of 152, 90.1%, unknown for one case) than for early neonatal deaths (71 of 96, 74.0%). Consequently, in 2013 there were 40 perinatal deaths for which an autopsy was not offered, constituting 8.6% of all 463 perinatal deaths. This is a smaller proportion than in 2012 when 52 (11.7%) of the 445 perinatal deaths were not offered an autopsy.

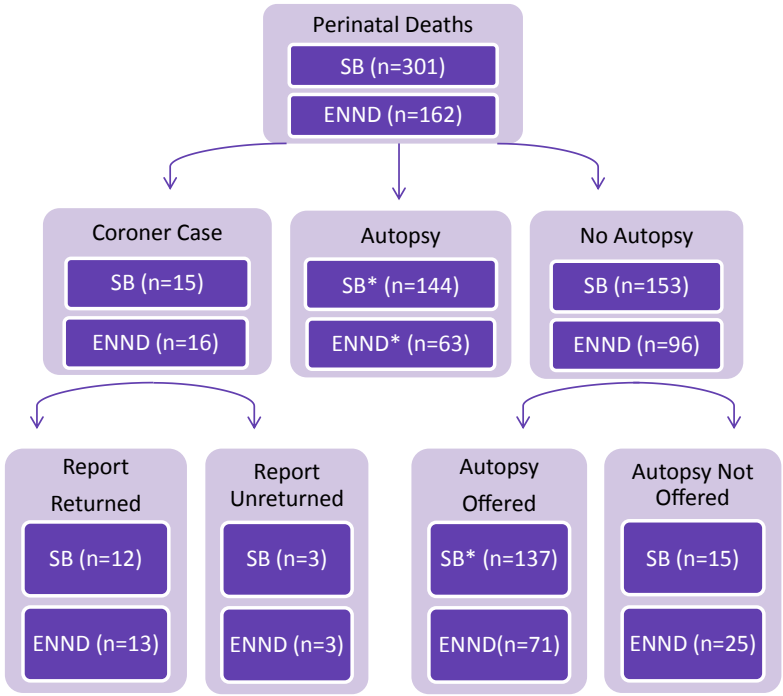



Figure 1.13: Flowchart describing autopsy-related steps taken after 463 perinatal deaths in 2013

Note: Autopsy unknown for four cases of stillbirth and three cases of early neonatal death. Autopsy offer unknown for one case of stillbirth.

The decision not to offer to undertake an autopsy may be influenced by the clinical scenario and the antenatal diagnosis. There was evidence to support this in relation to major congenital anomaly. The proportion of cases not offered an autopsy was higher if the perinatal death was due to a major congenital anomaly than if it the death was due to another cause (Table 1.19).

Table 1.19: Uptake and offer of autopsy of perinatal deaths due and not due to major congenital anomaly, 2013

| Autopsy | Stillbirth (N=296 of 301) | | Neonatal death (N=159 of 162) | |
|---|---|---|---|---|
| | Cause of death: major congenital anomaly | | Cause of death: major congenital anomaly | |
| | Yes (n=69) | No (n=227) | Yes (n=91) | No (n=68) |
| Performed | 25(36.2%) | 119(52.4%) | 35(38.5%) | 28(41.2%) |
| Offered | 36(52.2%) | 101(44.5%) | 37(40.7%) | 34(50%) |
| Not offered | 8(11.6%) | 7(3.1%) | 19(20.9%) | 6(8.8%) |

Note: Data on whether autopsy was performed and/or offered was incomplete for five cases of stillbirth and three cases of early neonatal death.

## Placental examination

The value of placental examination in determining cause of perinatal death is well documented.[34] In 2013, placental histology examinations were conducted for almost all stillbirths (n=292, 97.0%) and for 84.6% of early neonatal deaths (n=137). Thus, the rate of placental histology examination has increased for stillbirths from 93% in 2011 to 97% in 2013 and for early neonatal deaths from 69% in 2011 to 85% in 2013. Very similar levels of placental histology, of 94% for stillbirths and 86% for early neonatal deaths, were reported for Northern Ireland in 2013[35] compared to 87.2% of stillbirths in the UK as a whole.[36]

## Specific placental conditions

Abnormal placental findings have been classified and are presented under the following broad categories: maternal vascular malperfusion, fetal vascular malperfusion, cord pathology, placental maturation defect, chorioamnionitis, villitis and other. This is in keeping with recommendations in a forthcoming publication from an international consensus meeting of pathology.

Of the 292 stillbirths and 137 early neonatal deaths for which placental examinations were conducted, specific placental conditions in at least one of the above categories were reported in 176 (60.3%) of stillbirths and 65 (47.4%) of early neonatal deaths.

Table 1.20: Placental histology findings for stillbirths and early neonatal deaths, 2013

| | Stillbirth n(%) (N=292) | Neonatal death n(%) (N=137) |
|---|---|---|
| Maternal vascular malperfusion | 73(25.0) | 25(18.2) |
| Fetal vascular malperfusion | 38(13.0) | 9(6.6) |
| Cord pathology | 20(6.8) | 4(2.9) |
| Placental maturation defect* | 22(7.5) | 6(4.4) |
| Chorioamnionitis, placenta | 37(12.7) | 24(17.5) |
| Villitis | 10(3.4) | 4(2.9) |
| Other | 34(11.6) | 11(8.0) |
| Any placental condition | 176(60.3) | 65(47.4) |

*Placental maturation defect includes distal villous immaturity and delayed villous maturation.

Specific placental conditions were generally more prevalent among stillbirths than among cases of early neonatal death with the exception of chorioamnionitis which was reported in approximately one in six early neonatal deaths and one in eight stillbirths (Table 1.20). In the case of stillbirths, conditions within the maternal vascular malperfusion category were most commonly reported (25.0%).

The prevalence rates reported for some specific placental conditions in Table 1.20 are lower than those reported in previous studies.[37,38] Whether this reflects varying degrees of detection, reporting or interpretation of placental histology reports warrants further investigation. Submission of anonymised placental histology reports to the NPEC as part of this audit would facilitate standardised interpretation and classification of placental conditions at national level.

34 Korteweg FJ, Erwich JJ, Timmer A, van der Meer J, Ravise JM, Veeger NJ, Holm JP. Evaluation of 1025 fetal deaths: proposed diagnostic workup. Am J Obstet Gynecol 2012 206:53.e1-53.e12
35 Northern Ireland Maternal and Child Health. (2015) Perinatal mortality: Northern Ireland 2013. Belfast: Northern Ireland Public Health Agency.
36 Manktelow BM, Smith LK, Evans TA, Hyman-Taylor P, Kurinczuk JJ, Field DJ, Smith PW, Draper ES, on behalf of the MBRRACE-UK collaboration. Perinatal Mortality Surveillance Report UK Perinatal Deaths for births from January to December 2013. Leicester: The Infant Mortality and Morbidity Group, Department of Health Sciences, University of Leicester. 2015.
37 Beebe LA, Cowan LD, Altshuler G. The epidemiology of placental features: Associations with gestational age and neonatal outcome. Obstetrics & Gynecology. 87(5):771-778, 1996.
38 Mooney EE. Implantation and placenta; and Mooney EE, Doyle EM. Non-neoplastic maternal gestational diseases (2014). In: Mutter GL, Prat J, eds. Pathology of the Female Reproductive Tract. 3rd edition. London: Churchill Livingstone. ISBN 9780702044977

## Other examinations performed

External examination was made for approximately half of the 463 perinatal deaths in 2013 compared to 38.2% in 2012 (Table 1.21). X-Ray was also reported to have been performed more often following perinatal death in 2013 (25.5%) than in 2012 (14.2%). Computerised tomography scans and magnetic resonance imaging tests were rarely undertaken. External examination and X-ray were carried out marginally more often following cases on stillbirth in 2013 than for cases of early neonatal death.

Table 1.21: Other examinations performed in investigating perinatal deaths in 2012 and 2013

| Examination | Perinatal Deaths 2012 | Perinatal Deaths 2013 | Stillbirth n(%) 2013 | Neonatal death n(%) 2013 |
|---|---|---|---|---|
| External | 170(38.2) | 247(53.3) | 166(55.1) | 81(50.0) |
| X-Ray | 63(14.2) | 118(25.5) | 82(27.2) | 36(22.2) |
| CT scan | 2(0.4) | 7(1.5) | 0(0) | 7(4.3) |
| MRI | 4(0.9) | 0(0) | 0(0) | 0(0) |

Note: CT=Computerised tomography, MRI=magnetic resonance imaging

## Cytogenetic investigation in chromosomal disorders

Cytogenetic analysis is an important investigation in the diagnosis of chromosomal abnormalities. Some abnormalities are potentially recurrent and can be tested for in future pregnancies.[39] In the event of a chromosomal disorder, a specific question on the NPEC Perinatal Death Notification form asks how the diagnosis was made. A major congenital chromosomal disorder was the main cause in 58 perinatal deaths in 2013 (33 stillbirths and 25 early neonatal deaths). For two thirds of these cases (n=38, 65.5%), the diagnosis was made by cytogenetic analysis (n=23 stillbirths, 69.7%; n=15 neonatal deaths, 60.0%). In 2012, there were 55 perinatal deaths due to a major congenital chromosomal disorder and for three quarters of those cases the diagnosis was made by cytogenetic analysis (n=41, 74.5%).

39 Clinical Practice Guideline No 4 (2011). Investigation and management of late fetal intrauterine death and stillbirth: Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Strategy and Clinical Programmes, Health Service Executive.

# 2. Invited commentary: The impact of stillbirth

In the developed world, one in 200 infants is stillborn. This is a devastating outcome of pregnancy for parents and for the healthcare professionals who look after them. Stillbirth is still 10 times more common than sudden infant death syndrome and accounts for 70% of all perinatal deaths. This latest Perinatal Mortality Annual Report from NPEC describes 301 infants who were stillborn in 2013.

Many stillbirths do remain unexplained, but an unexplained death may in reality be an un-investigated one. Stillbirths deserve the same systematic evaluation as adult deaths, yet the study of specific causes of stillbirth has been historically hindered by the absence of uniform protocols of investigation, lack of agreement on definitive classification systems, as well as the extent of post-mortem assessment performed. In general, the most common causes of stillbirth are investigated, as well as those conditions that might predispose couples to recurrent stillbirth. Understanding reasons helps parents recover, but may also identify recurrence risks and even identifying a sporadic cause has merit as it can bring closure and provide reassurance. An important national advancement has been NPEC's development and implementation in 2011 of a comprehensive data collection tool and classification system for perinatal deaths.

Falling post-mortem rates, related to public concerns regarding perinatal autopsy, has prompted a search for non-invasive alternatives, including post-mortem imaging, and for predictive markers of placental dysfunction and incipient fetal growth restriction. Despite this, the conventional post-mortem examination or autopsy remains the gold standard for determining the cause of death. Clinicians should continue to advocate for this rather than inferring a cause and the important role of specialist perinatal pathology within maternity services needs greater focus. Many of the broad categories of cause of death, including unexplained stillbirth, are thought to be related to placental function, and while placental abnormalities are estimated to occur in over 50% of stillbirths, they are still poorly understood and sometimes variously reported. Internationally, several risk factors have now been associated with stillbirth, including advanced maternal age, high body mass index, maternal ethnicity, fetal growth restriction but understanding of the epidemiology remains limited. Numerous social, behavioural and lifestyle risk factors are reported to be associated with stillbirth, but these links are complex, and psychosocial and biological factors may interact together to increase the risk.

The death of an infant is one of the most stressful life events that an adult experiences. There is significant psychological morbidity associated with prenatal loss at any gestation and effects on physical and emotional wellbeing may be long-lasting. Provision of an empathetic environment with psychological support at the time of loss is now an accepted part of care, albeit without much evidence yet of improved health outcomes. Only a few studies have addressed the lived experience of stillbirth and there is still relatively little qualitative research showing how bereaved parents make sense of their loss. In addition to the impact on parents and their families, stillbirth has also been demonstrated to have a considerable impact on healthcare professionals. Studies reveal a consistent account of personal and professional burden following stillbirth. Given the extensive impact of stillbirth on all involved, it is imperative to understand the underlying causes. Further, identification of mothers at risk for pregnancy loss is a necessary step to effective intervention and prevention, and the intensity of prenatal care can then be matched to each woman's risk profile.

### Impact on parents and families

The recognition of stillbirth as a significant bereavement is relatively new, but the death of an infant is now acknowledged as a hugely stressful life event. Perinatal grief is a distinctive grief with lasting and lifelong impact for parents, who often have complex emotional and psychological needs following stillbirth.

Many short and long-term negative outcomes for parents have been reported in the aftermath of stillbirth, including anxiety, depressive symptoms, post-traumatic stress, suicidal ideation, guilt, social phobia and remorse. Studies have demonstrated that the impact of stillbirth contributes significantly to relationship strain and breakdown. Factors which have been suggested to increase the risk of adverse psychological outcomes for parents after stillbirth include: inadequate social support, traumatic circumstances surrounding the death, difficulties in coping with a crisis in the past, problematic relationships and the presence of other life crises. Of concern is the extensive literature regarding the ongoing morbidity and mortality that exists for families who have experienced infant bereavement, including significantly higher levels of anxiety and depression in pregnant mothers who had previously had a perinatal loss with a negative impact on attachment to the subsequent child, as well as evidence of increased mortality in bereaved parents. Stillbirth has also been shown to have a negative impact on siblings, grandparents, and other family members.

Bereavement care following stillbirth has developed over the last twenty years to reflect the increasing understanding of grief. Traditional models encouraged a focus on cutting ties with the loved one and moving on, whereas modern models recognise the value of continuing bonds and creating meaning. Stillbirth bereavement care now aims to support these grieving tasks by facilitating the parents' expression of grief, through ensuring a sensitive non-traumatising experience during which they spend time as parents with their baby, supporting them in creating memories and helping them with understanding through investigation.

The provision of support for parents following stillbirth is therefore a key part of overall care from the maternity services. This support should be initiated from the time of diagnosis and extend through the care provided in hospital and then following discharge for as long as is necessary. Dedicated bereavement teams contribute much to the support offered to parents, where trained professionals can provide specialised and appropriate person-centred care and follow-up investigations. There is however continuing inconsistency in the availability of bereavement support across the Irish maternity services in 2015, and a heavy reliance on the voluntary charitable sector to meet the needs of bereaved parents and families.

Research has suggested that the role of practitioners in the handling of death and their interaction with the bereaved from the moment of breaking the news of death influences the intensity of grief and has the potential to positively impact on the grief experience of bereaved parents. However, poor communication can add to parental distress and increase dissatisfaction with care. There is, thankfully, increasing recognition of the need to offer guidance and training to health-care professionals involved in communicating bad news. Creation of an empathetic, caring environment, and strategies to enable the family to accept the reality of stillbirth, are now an accepted part of standard care and social support. Further, provision of interventions such as psychological support or counselling, or both, has been suggested to improve outcomes for families after a perinatal death, although evidence for this is still limited.

Surveys of bereaved parents highlight the critical importance of the quality of parents' interactions with staff. While the specialised role of bereavement midwives in particular, and other members of the bereavement team is always acknowledged, it is clear that parents expect the importance of kindness and sensitivity to extend to all hospital staff including clerical, security, catering, medical, chaplaincy and midwifery. The use of an alert

or 'bereavement' sticker on the cover of the hand held patient file, as used in several UK and Irish hospitals, has the potential to remind staff to be sensitive, as does the display of a similar symbol in clinical areas. A study on bereaved parents' experience of stillbirth in UK hospitals agreed that, "positive memories and outcomes depend as much on genuinely caring staff attitudes and behaviours as on high-quality clinical procedures". In this way it can be seen that empathic care and sensitive communication from the bereavement team alone is not sufficient. The entire hospital must adopt a considerate and supportive approach toward parents and families bereaved by stillbirth. The conclusion of Soo Downe's 2013 paper on bereaved parents experience of stillbirth is a worthwhile one to remember: "*all staff who encounter parents in this situation need to see each meeting as their one chance to get it right.*"

### Impact on staff

The lived experiences of bereaved parents have contributed much to the published literature on stillbirth. However, it is increasingly recognised that stillbirth has a considerable impact on the personal and professional wellbeing of healthcare professionals. The impact of this emotional burden in the wider healthcare field is now being openly documented. In a questionnaire study of US obstetricians in 2008 seventy-five percent of respondents acknowledged that caring for women following stillbirth took a large emotional toll on the obstetrician. A recent Irish study confirmed that the emotional burden associated with stillbirth is considerable and revealed the complexity for medical consultants within the multi-disciplinary team. Despite the impact of stillbirth, no consultant had received formal training in perinatal bereavement care. This study highlighted both a gap in training and the implications of stillbirth on obstetricians professionally and personally, recommending the provision of support, ongoing education and the need for self-care.

In a meta-analysis of studies (n=20) published between 2000-2015, conducted for the upcoming 2015 Lancet stillbirth series, all of the studies reviewed reported substantial personal and professional impacts on staff following stillbirth. Four major qualitative themes emerged from the review of these papers: psychological impact, professional impact, need for support, and positive effects for staff. Psychological impact was most frequently reported with somatic effects such as trauma symptomatology, diminished emotional availability, stress, and affective states such as grief, guilt, anger, self-blame, self-doubt, anxiety and sadness. The professional impact of stillbirth was characterised by fear of litigation or loss of livelihood as well as fear of disciplinary action. The majority of studies highlighted the need for further education and professional support for staff in psychosocial care and communication skills. Lack of institutional and structured peer support was also highlighted, and many studies found that peer support, although valuable, was too informal. Interestingly, staff who felt they had received adequate training in stillbirth care reported less guilt and less fear of litigation. Only six studies noted the positive outcomes reported by staff such as a sense of 'privilege', 'personal growth' and the development of a 'special bond' with parents. In four studies, staff reported more confidence with fewer negative effects, where they had more direct clinical experience of stillbirth.

The Irish Medical Council's 2014 report "*Your training counts*" states that there is ample evidence to show that "good health and wellbeing contribute to good professional practice". It is acknowledged therein that healthcare professionals must provide safe effective and compassionate care for patients and families at times of great distress, in a demanding healthcare context, while trying to maintain professional competence. However, historically, healthcare professionals, and doctors in particular, have been slow to recognize the profound effect adverse medical outcomes, such as the death of a patient, can have on their mental and physical health. Doctors have higher rates of mental health disorders, including depression, anxiety, substance misuse, and "burn out" than other

occupational groups yet are reluctant to access services that might help.

There is now an increasing body of research looking at burnout and compassion fatigue in healthcare, although for reasons that are unclear very little of this to date has focused specifically on the maternity services. Compassion fatigue, defined in the literature as the reduced capacity for empathy toward patients resulting from repeated exposure to their trauma, has been linked with maladaptive coping mechanisms to stress, chronic exhaustion, absence of appropriate debriefing after adverse events and lack of training in dealing with death. Burnout, a concern in fields dealing with trauma and acute stress, also develops in response to intense interpersonal situations with high emotional and cognitive demands. It has been linked to longer working hours and is experienced more often by those who work in specialties with proportionally higher direct patient contact.

Over the past decade, system changes in healthcare have necessarily focused on disclosure, reporting, and the patient safety culture. However, little attention has been paid to creating systems that help the healthcare providers, who are involved as the 'second victims' after an adverse event such as stillbirth represents. The literature highlights the importance of staff education and professional support as gaps in existing service provision and as areas that require increased attention in healthcare systems. Further research on support interventions for staff and the effect of this staff support on patient care outcomes are needed. Finally, as colleagues in palliative care medicine have written: "the idea of 'self-care' may seem a selfish irrelevance and an unjustifiable luxury. In fact, self-care is an essential part of the therapeutic mandate."

## Impact on society

The impact of stillbirth on society ranges from the obvious loss of a valued human life to the effect of this loss directly on families, healthcare systems, welfare systems and the workplace. There is a paucity of information in the published literature to quantify the exact economic cost of stillbirth to society, but these costs can be loosely described as direct and indirect. Direct costs associated with stillbirth include those related to its management and the associated medical investigations, costs of funerals and burial arrangements, as well as the increased costs of care for subsequent pregnancies following stillbirth. Indirect costs are more difficult to quantify and include the longer-term costs to society following the grief and psychological symptoms that occur as part of the impact of stillbirth on parents. Other indirect costs include lack of productivity through employment absence and reduction in working hours. Acknowledgement of the personal and professional cost of stillbirth on staff raises important issues of staff wellbeing and governance, which in turn directly affect both the financial and human costs of providing care and families' experiences.

## How to make a difference

*Healthcare Systems*

Sands, the UK Stillbirth and Neonatal Death Society founded in 1978, recommends five key ways in which maternity units can improve the care for parents whose baby dies before, during or after birth (https://www.uk-sands.org/professionals/principles-of-care/5-ways-to-improve-care). These are (1) bereavement care training for all staff, (2) access to trained bereavement care midwives for bereaved parents and staff support, (3) at least one dedicated bereavement room, (4) bereavement care literature and (5) post mortem consent information for parents and staff training in consent. This is because "the quality of care that bereaved families receive when their baby dies has long-lasting effects. Good care cannot remove parents' pain and grief, but poor care can and does make things much worse."

National clinical guidelines on the Investigation and Management of Late Fetal Intrauterine Death and Stillbirth were published in 2011, with 22 key recommendations setting out the expectation of standards of care in all Irish hospitals (http://www.rcpi.ie/article.php?locID=1.5.71.492). The guideline highlights that skilled, sensitive and caring treatment in the time surrounding

pregnancy loss can positively impact on the grief experience of bereaved parents and recommends that supportive care should be made available to all. The introduction and, it is expected, implementation of these stillbirth guidelines ensures that, at a very minimum, parents should expect to receive comprehensive care, thorough investigation, and bereavement support from diagnosis to delivery and postnatally following stillbirth.

The HSE has recently launched a national public consultation process on draft Bereavement Care Standards following Pregnancy Loss & Perinatal Death, which, it is hoped, will be published in 2016 (http://www.hse.ie/bereavementcarestandards/). These Standards are important to ensure improvements in key aspects of bereavement care for women, parents and families who experience stillbirth in Ireland, including the development of bereavement specialist teams in all maternity units and the provision of training and support for all healthcare professionals involved in caring for the bereaved.

## Stillbirth Research, Confidential Enquiries and Clinical Audit

Stillbirth is a highly significant topic of research. While stillbirth has been for decades a largely under-prioritised and under-researched problem, stillbirth research – that is, the investigation of causes of stillbirth as well as development of effective interventions to prevent stillbirth - has now been classified as a specific global research priority.

Stillbirth has become an international focus of interest and concern as a preventable death, with the Global Alliance to Prevent Prematurity and Stillbirth (GAPPS) and the World Health Organization naming reduction in stillbirth rates as a key goal to improve pregnancy outcome. The Lancet's Stillbirths Series listed stillbirth research priorities in 2011. These included: (i) developing repositories of human samples from stillbirths (ii) defining pathophysiological pathways leading to stillbirth associated with maternal disease, fetal growth restriction or placental dysfunction, (iii) investigating maternal lifestyle consumptions associated with stillbirth and (iv) determining optimal antenatal surveillance with interventions to reduce stillbirth. There has already been a significant increase in stillbirth research output commensurate with this attention, assisted by the increasing public awareness of the impact of perinatal grief.

Consideration should be given to establishing a Confidential Enquiry into Perinatal Death in Ireland, in the same way as the Maternal Death Enquiry (MDE) Ireland has conducted confidential reviews into maternal deaths since 2009. Confidential Enquiries focus on improving health care by collecting evidence on aspects of care, identifying any shortfalls in this, and disseminating recommendations based on these findings. In this process, enquiry panels comprise clinicians from relevant specialties, who are independent of the hospital where the patient died and who are unaware of the clinicians concerned with the patient's care. The purpose of a Confidential Enquiry is specific; identifying suboptimal patterns of practice and service provision related to the deaths, making recommendations for improvements in clinical care and suggesting directions for future research and audit.

Finally, robust perinatal audit is increasingly established throughout the developed world and aims to identify antecedent conditions and risk factors associated with stillbirth. It has proved an important tool for reduction of perinatal mortality and assessment of quality of perinatal care. The work of the National Perinatal Epidemiology Centre in presenting the results of clinical audit in successive annual Perinatal Mortality Reports is therefore to be commended.

## Acknowledgments

The contribution of work by Rev. Daniel Nuzum, Ms. Orla O'Connell and Dr. Karen McNamara to this commentary is acknowledged.

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# 3. Stillbirths: Specific findings

## Cause of death in stillbirths

Major congenital anomaly was the primary cause of death in almost one in four (n=69, 22.9%) of the 301 stillbirths that occurred in 2013 (Figure 3.1). There was a chromosomal disorder in almost half of the 69 stillbirths due to congenital anomaly (n=33, 47.8%). In these cases, the majority were diagnosed by cytogenetic analysis (n=23, 69.7%). Anomalies of the central nervous system and of the cardiovascular system caused a further 10 (14.5%) and nine (13.0%) stillbirths, respectively.

Specific placental conditions were diagnosed in two-thirds (66.3%) of stillbirth cases and a placental condition, most commonly placental insufficiency, was classified as the main cause of death of almost one in four stillbirths (n=66, 21.9%). One in ten stillbirths (n=30, 10.0%) were due to mechanical factors, the vast majority of which were due to the umbilical cord being around the baby's neck or another entanglement or knot in the umbilical cord. Antepartum or intrapartum haemorrhage was the main cause of death in 26 cases of stillbirth (8.6%) and placental abruption was involved in all of these cases. For the 17 stillbirths with infection as the main cause of death, half involved chorioamnionitis (n=9).

For approximately one in four stillbirths (n=71, 23.6%) the cause of death was unexplained. While this is significantly lower than the proportion previously reported as unexplained using the Wigglesworth Classification System, it is marginally higher than in the two previous years. For half of the stillbirths of unexplained cause (n=36, 50.7%), antecedents or associated obstetric factors were present but did not cause the death. For more than one third of unexplained stillbirths (n=26, 36.6%), it was reported that there were no antecedents or associated obstetric factors. For all but one of these 26 cases an autopsy was performed (n=12, 46.2%) or was offered (n=13, 50.0%). A detailed listing of the main cause of death for the 301 stillbirths is given at the end of this section of the report.

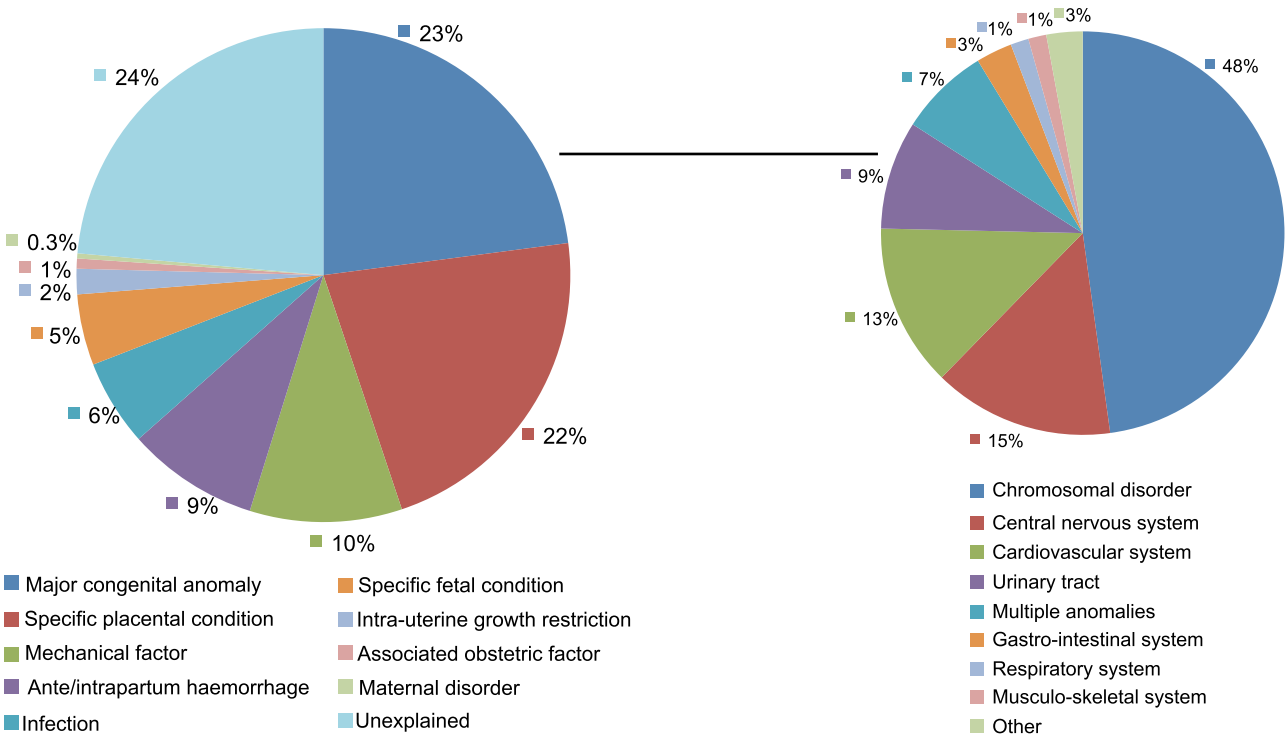


Figure 3.1: Primary cause of death in stillbirths (left-hand chart) and detailed cause in cases of major congenital anomaly (right-hand chart)

## Management of women experiencing antepartum stillbirths

Factors influencing the delivery management of women experiencing antepartum stillbirths include maternal choice, maternal wellbeing, risk of developing severe medical complications and previous obstetric history. Management of clinical care may involve planned induction of labour, awaiting spontaneous labour or in some cases elective delivery by caesarean section.[40]

In 2013, labour was induced for two-thirds of the 269 women who experienced antepartum stillbirth (n=175, 65.1%) whereas labour was spontaneous for 24.2% (n=65). It can be seen from Figure 3.2 that the time from diagnosis of fetal demise to delivery was different for women whose labour was induced than it was for women whose labour was spontaneous. The confirmation of death and delivery took place on the same day for three quarters (n=63 of 84, 75.0%) of the women whose labour was spontaneous. For women whose labour was induced, it was common for up to three days to pass between diagnosis and delivery.

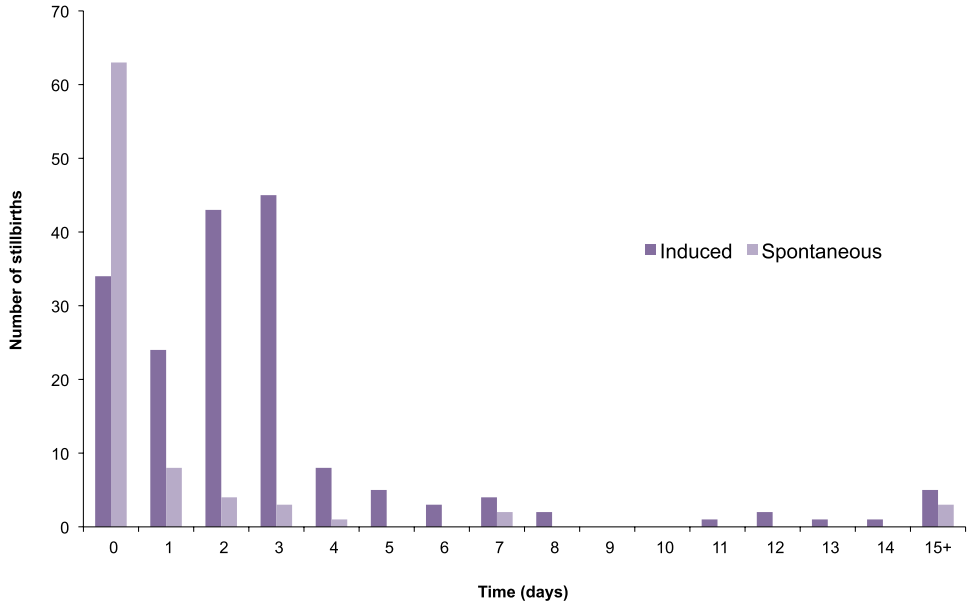


Figure 3.2: Time from confirmation of fetal demise to stillbirth delivery for women with induced and spontaneous labour

Vaginal birth is the recommended mode of delivery for most women experiencing antepartum stillbirth, but caesarean section may be clinically indicated in some cases.[41] Spontaneous vaginal delivery was the mode of delivery in more than two-thirds of cases of antepartum stillbirth (70.6%) compared to approximately half of the cases of intrapartum stillbirth (n=13, 54.2%).

In 24 cases of antepartum stillbirth (9.1%) the intended mode of delivery was a planned caesarean section and ultimately, caesarean section was the mode of delivery for 34 women (12.6%; 28 pre-labour caesarean sections and six caesarean sections performed after onset of labour).

Of the 34 women who were delivered by caesarean section, the indication for caesarean section was classified as 'elective' in approximately 40% of the cases, 30% were 'urgent' and 30% were 'emergency' (Table 3.1). Thirteen (38.2%) of the 34 women had a caesarean section previously, one in three (n=11, 33.3%; unknown for one case) had a multiple delivery and eight (25.0%; unknown for two cases) had a placental abruption, all factors that may have influenced the mode of delivery.

The location of delivery of antepartum stillbirths in all but two cases (n=267, 99.3%) was in obstetric-led maternity units. The two exceptions were born before arrival to hospital.

40 Clinical Practice Guideline No 4 (2011). Investigation and management of late fetal intrauterine death and stillbirth: Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Strategy and Clinical Programmes, Health Service Executive.
41 Clinical Practice Guideline No 4 (2011). Investigation and management of late fetal intrauterine death and stillbirth: Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Strategy and Clinical Programmes, Health Service Executive.

Table 3.1: Indication for caesarean section in women experiencing antenatal stillbirth in 2013

| Indication for caesarean section | n(%) |
|---|---|
| Elective: At a time to suit the woman or the maternity team | 13(39.4) |
| Urgent: Maternal or fetal compromise which is not immediately life threatening | 10(30.3) |
| Emergency: Immediate threat to life of woman or baby | 10(30.3) |

Note: Indication unknown in one case

## Intrapartum stillbirths

It has been suggested that the comparatively low proportion of intrapartum stillbirths in high-income countries indicates that fetal deaths occurring in labour, in non-anomalous babies, are most likely preventable with quality intrapartum care.[42] Intrapartum deaths in this audit were identified by a specific question on the NPEC Perinatal Death Notification Form as to whether the baby was alive at the onset of care in labour. This was not known in eight cases (Table 3.2), four of which involved the baby being born before arrival to hospital. There were 24 cases of stillbirth where the baby was known to be alive at the onset of care in labour. Thus, intrapartum deaths accounted for 8.0% of stillbirths in Ireland in 2013. This was lower than the proportion of stillbirths associated with labour in UK countries in 2013, ranging from 8.4% in England to 8.6% in Northern Ireland, 10.9% in Wales and 13.2% in Scotland.[43]

Table 3.2: Life status of baby at the onset of care in labour for stillbirths in 2013

| | n(%) |
|---|---|
| Baby alive at onset of care in labour | 24(8.0%) |
| Baby not alive at onset of care in labour | 256(85.0%) |
| Never in labour | 13(4.3%) |
| Not known | 8(2.7%) |

Of the 24 intrapartum deaths, 10 (41.7%) were due to major congenital anomaly and four (16.7%) were due to placental abruption. Conditions related to the umbilical cord and to the placenta each caused another two cases. In three cases the cause of death was classified as unexplained though some antecedent or associated obstetric factors were reported. There was no clustering by hospital in the intrapartum deaths due to causes other than congenital anomaly. It was reported that a local hospital review was undertaken into 10 of the 24 intrapartum deaths (41.7%).

42 Darmstadt G, Yakoob M, Haws R, Menezes E, Soomro T and Bhutta Z. Reducing stillbirths: interventions during labour. BMC Pregnancy and Childbirth 2009;9 (Suppl 1):s6

43 Manktelow BM, Smith LK, Evans TA, Hyman-Taylor P, Kurinczuk JJ, Field DJ, Smith PW, Draper ES, on behalf of the MBRRACE-UK collaboration. Perinatal Mortality Surveillance Report UK Perinatal Deaths for births from January to December 2013. Leicester: The Infant Mortality and Morbidity Group, Department of Health Sciences, University of Leicester. 2015.

Table 3.3: Stillbirth main cause of death in 2011-2013, NPEC Classification System

| Stillbirths | 2011 N=318 | 2012 N=304 | 2013 N=301 |
|---|---|---|---|
| **Major congenital anomaly** | **81(25.5%)** | **80(26.3%)** | **69(22.9%)** |
| Central nervous system | 10 | 11 | 10 |
| Cardiovascular system | 10 | 5 | 9 |
| Respiratory system | - | 1 | 1 |
| Gastro-intestinal system | 3 | 2 | 2 |
| Musculo-skeletal system | 3 | 1 | 1 |
| Multiple anomalies | 10 | 10 | 5 |
| Chromosomal disorders | 39 | 38 | 33 |
| Metabolic disorders | - | - | - |
| Urinary tract | 2 | 2 | 6 |
| Other major congenital anomaly | 4 | 10 | 2 |
| **Specific placental conditions** | **52(16.4%)** | **73(24.0%)** | **66(21.9%)** |
| Maternal vascular malperfusion* | | | 22 |
| Fetal vascular malperfusion* | | | 16 |
| Cord pathology* | | | 9 |
| Placental maturation defect* | | | 8 |
| Chorioamnionitis, placenta | - | - | 1 |
| Villitis | - | 4 | 2 |
| Other placental condition | 19 | 20 | 8 |
| **Mechanical** | **20(6.3%)** | **25(8.2%)** | **30(10.0%)** |
| Prolapse cord | 1 | 1 | 2 |
| Cord around neck | 8 | 14 | 18 |
| Other cord entanglement or knot | 11 | 10 | 9 |
| Uterine rupture before labour | - | - | 1 |
| Uterine rupture during labour | - | - | - |
| Mal-presentation | - | - | - |
| Shoulder dystocia | - | - | - |
| **Antepartum or intrapartum haemorrhage** | **35(11.0%)** | **21(6.9%)** | **26(8.6%)** |
| Praevia | 2 | - | - |
| Abruption | 33 | 21 | 26 |
| Uncertain haemorrhage | - | - | - |

*Reported abnormal placental histology was not classified under these categories for the years 2011 and 2012; Placental maturation defect includes distal villous immaturity and delayed villous maturation.

Table 3.3: Stillbirth main cause of death in 2011-2013, NPEC Classification System (Contd.)

| Stillbirths | 2011 N=318 | 2012 N=304 | 2013 N=301 |
|---|---|---|---|
| **Infection** | **17(5.3%)** | **16(5.3%)** | **17(5.6%)** |
| Maternal | | | |
| Bacterial | 1 | - | - |
| Syphilis | 1 | - | - |
| Viral diseases | - | 2 | 1 |
| Protozoal | - | - | - |
| Group B Streptococcus | 2 | 1 | 3 |
| Other maternal infection | - | - | 1 |
| Ascending infection | | | |
| Chorioamnionitis | 13 | 11 | 9 |
| Other ascending infection | - | 2 | 3 |
| **Specific fetal conditions** | **15(4.7%)** | **9(3.0%)** | **14(4.7%)** |
| Twin-twin transfusion | 5 | 4 | 6 |
| Feto-maternal haemorrhage | 5 | 2 | 4 |
| Non immune hydrops | 3 | - | 1 |
| Iso-immunisation | - | - | - |
| Other fetal condition | 2 | 3 | 3 |
| **Intra-uterine growth restriction** | **17(5.3%)** | **6(2.0%)** | **5(1.7%)** |
| IUGR - Suspected antenatally | 4 | 4 | 2 |
| IUGR - Observed at delivery | 7 | 1 | 1 |
| IUGR - Observed at post mortem | 6 | 1 | 2 |
| **Associated obstetric factors** | **7(2.2%)** | **3(1.0%)** | **2(0.7%)** |
| Intracranial haemorrhage | - | - | - |
| Birth injury to scalp | - | - | - |
| Fracture | - | - | - |
| Other birth trauma | - | - | - |
| Intrapartum asphyxia | 5 | - | - |
| Polyhydramnios | - | - | - |
| Oligohydramnios | - | - | - |
| Premature rupture of membranes | - | - | - |
| Spontaneous premature labour | - | 2 | 2 |
| Other obstetric factors | 2 | 1 | - |
| **Maternal disorder** | **6(1.9%)** | **0(0.0%)** | **1(0.3%)** |
| Pre-existing hypertensive disease | 1 | - | - |
| Diabetes | 2 | - | - |
| Other endocrine conditions | - | - | - |
| Thrombophilias | - | - | - |
| Obstetric cholestasis | - | - | - |
| Drug misuse | - | - | - |
| Uterine anomalies | 1 | - | - |
| Other maternal disorder | 2 | - | 1 |
| **Hypertensive disorders of pregnancy** | **4(1.3%)** | **2(0.7%)** | **0(0.0%)** |
| Pregnancy induced hypertension | 1 | - | - |
| Pre-eclampsia toxaemia | 3 | 2 | - |
| HELLP syndrome | - | - | - |
| Eclampsia | - | - | - |
| **Unexplained** | **64(20.1%)** | **69(22.7%)** | **71(23.6%)** |
| No antecedents or associated obstetric factors | 41 | 30 | 26 |
| Antecedents or associated obstetric factors present | 20 | 38 | 36 |
| Very limited information available | - | - | 4 |
| Pending post mortem or other investigation | 3 | 1 | 5 |

# 4. Early neonatal deaths: Specific findings

## Cause of early neonatal death

The cause of early neonatal deaths was classified using both the NPEC Neonatal Classification System and the NPEC Maternal and Fetal Classification System in order to identify both the primary neonatal condition causing the death and the underlying main antecedent or obstetric factor associated with the death.

Major congenital anomaly was the primary cause of death of more than half (n=92, 56.8%) of the 162 early neonatal deaths (Figure 4.1). Respiratory disorder was the only other common main cause of death, accounting for one in three (n=53, 32.7%) early neonatal deaths. Neurological disorder was the main cause in 6.2% of cases. One death (0.6%) was unexplained pending post mortem or other investigation. A detailed listing of the main cause of death for the 162 early neonatal deaths is given at the end of this section of the report.

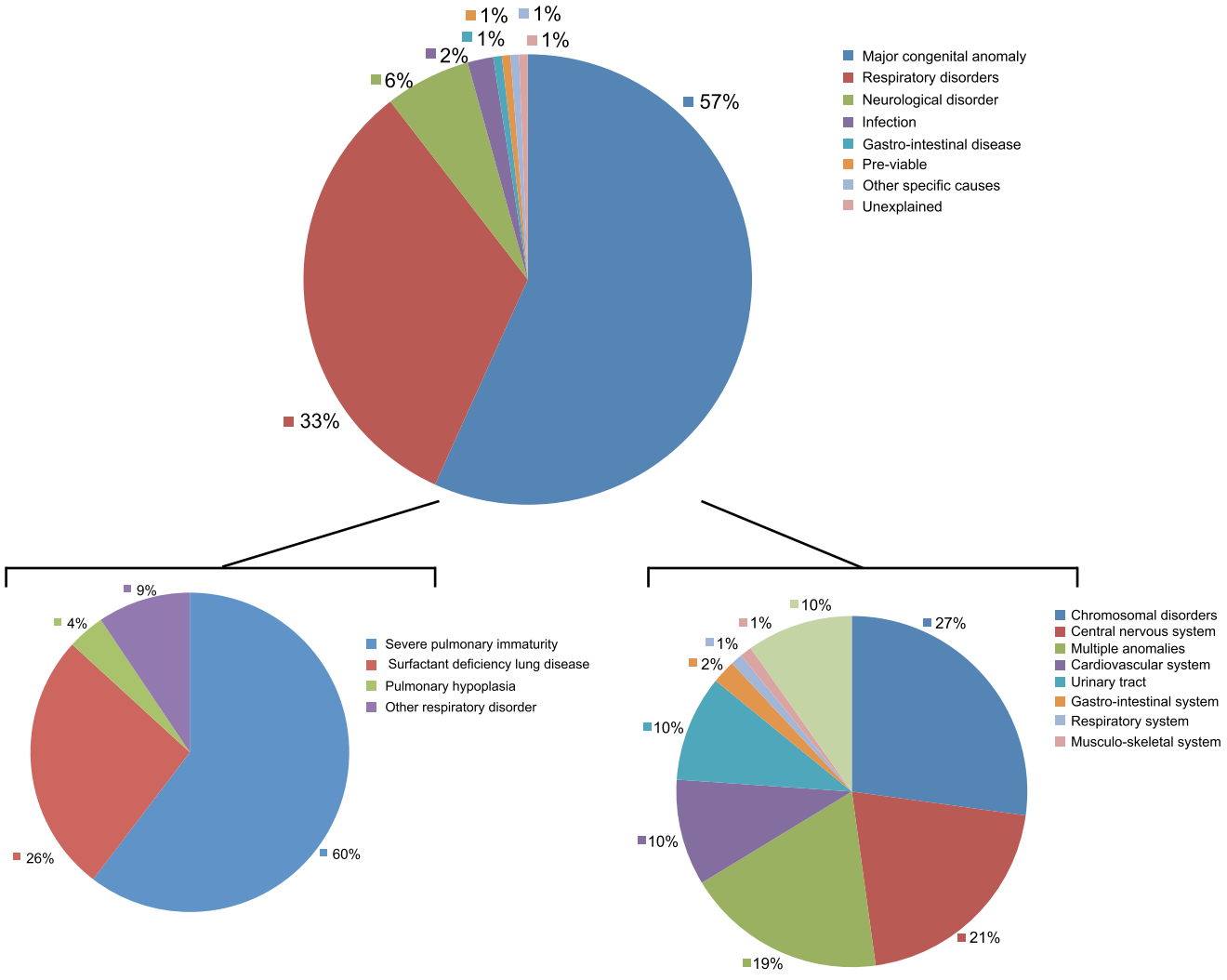


Figure 4.1: Primary cause of early neonatal death (upper chart) and detailed cause in cases of respiratory disorder (lower left-hand chart) and cases of major congenital anomaly (lower right-hand chart)

### Major congenital anomalies

The type of major congenital anomaly that caused 92 of the 162 neonatal deaths is illustrated in Figure 4.1. One in four were due to a chromosomal disorder (n=25, 27.2%), one in five (n=19, 20.7%) were due to anomalies related to the central nervous system and a similar proportion were due to multiple abnormalities (n=17, 18.5%). Anomalies of the cardiovascular system and of the urinary tract each accounted for a further 10% of these deaths. For most of the 25 neonatal deaths attributed to a chromosomal disorder the diagnosis was made by cytogenetic analysis (n=15, 60.0%).

### Respiratory disorders

Of the 53 early neonatal deaths caused by respiratory disorder, 60% (n=32, 60.4%) were due to severe pulmonary immaturity. Surfactant deficiency lung disease caused 14 neonatal deaths (Figure 4.1). All but three of the 53 early neonatal deaths attributed to respiratory disorder occurred in babies delivered before 28 weeks gestation (Table 4.1). This pattern of gestational age was in marked contrast with the early neonatal deaths due to major congenital anomaly and those due to other causes (Table 4.1).

Table 4.1: Gestational age distribution in neonatal deaths by broad main cause of death in 2013

| Broad main cause of death | <22 weeks | 22-27 weeks | 28-31 weeks | 32-36 weeks | 37-41 weeks | ≥42 weeks |
|---|---|---|---|---|---|---|
| Respiratory disorder | 1 | 49 | 2 | 1 | - | - |
| | (1.9%) | (92.5%) | (3.8%) | (1.9%) | | |
| Major congenital anomaly | - | 9 | 4 | 41 | 36 | 2 |
| | | (9.8%) | (4.3%) | (44.6%) | (39.1%) | (2.2%) |
| Other | 1 | 4 | 1 | 6 | 4 | - |
| | (6.3%) | (25.0%) | (6.3%) | (37.5%) | (25.0%) | |

### Neurological disorders

A neurological disorder was attributed as the main cause of ten early neonatal deaths. For nine of these cases, the condition involved was hypoxic ischaemic encephalopathy (HIE). Four of the nine HIE cases occurred in babies with a gestational age of 37-41 weeks. These four perinatal deaths had an autopsy performed and became coroner's cases. Table 4.2 details the gestational age, customised birthweight centile and main antecedent or obstetric factor associated with the ten early neonatal deaths attributed to neurological disorders.

Table 4.2: Details of early neonatal deaths due to neurological disorders in 2013

| Neurological Disorder | Gestational age | Birthweight centile | Main antecedent or obstetric factor associated with the death |
|---|---|---|---|
| IVH/PVH | 23 | 8th | Spontaneous premature labour |
| HIE | 34 | 52nd | Fetal vascular malperfusion |
| HIE | 36 | 31st | Placental abruption |
| HIE | 36 | 72nd | Placental abruption |
| HIE | 35 | 16th | Maternal vascular malperfusion |
| HIE | 35 | 93rd | Placental maturation defect |
| HIE | 40 | 2nd | Placental maturation defect |
| HIE | 40 | 69th | Fetal vascular malperfusion |
| HIE | 40 | 20th | Intrapartum uterine rupture |
| HIE | 41 | 14th | Cord pathology |

Note: IVH/PVH = Intraventricular/periventricular haemorrhage; HIE = hypoxic ischaemic encephalopathy

## Condition and management at birth

The NPEC Perinatal Death Notification Form records the condition, in terms of respiratory activity and heart rate shortly after delivery, of babies who die in the neonatal period. For most of these babies (n=93, 58.5%; unknown for three cases), spontaneous respiratory activity was absent or ineffective at five minutes following delivery and for 40% (n=64, 40.5%, unknown for four cases) the heart rate was persistently less than 100 beats per minute.

In most cases of early neonatal death, active resuscitation was offered in the delivery room (Table 4.3). In three quarters of the cases where active resuscitation was not offered (n=50, 73.5%) major congenital anomaly was the cause of death and all but two of the remainder were attributed to severe pulmonary immaturity (n=16, 23.5%).

Almost half of the babies were admitted to a neonatal unit in the hospital of delivery and one in ten babies were transferred to another unit (Table 4.3). Such admission and transfer depended on whether active resuscitation had been offered in the delivery room. Admission to a neonatal unit followed three quarters of the cases offered active resuscitation compared to 7% not offered active resuscitation. One in seven cases offered active resuscitation were transferred to another unit compared to one baby not offered active resuscitation.

Table 4.3: Management of neonate at birth who subsequently died within the first week of life

| Management | Active resuscitation offered * | | All |
|---|---|---|---|
| | Yes (91, 57.2%) | No (68, 42.8%) | 162 |
| Baby admitted to neonatal unit | 71 (78.0%) | 5 (7.4%) | 78 (48.1%) |
| Baby transferred to another unit | 13 (14.3%) | 1 (1.5%) | 17 (10.5%) |

*active resuscitation in the delivery room includes BMV, PPV, intubation, cardiac massage.
Note: Data on active resuscitation was unknown for three cases.

## Age of neonate at death

Two thirds of the early neonatal deaths occurred within 24 hours of delivery (Table 4.4). Major congenital anomaly and severe pulmonary immaturity were the main cause of death in 58.9% (n=63) and 26.2% (n=28) of these cases, respectively.

Table 4.4: Age of neonate at death

| Completed days | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|---|
| Number | 107 | 25 | 13 | 4 | 3 | 8 | 2 |
| % | 66.0 | 15.4 | 8.0 | 2.5 | 1.9 | 4.9 | 1.2 |
| Cumulative % | 66.0 | 81.5 | 89.5 | 92.0 | 93.8 | 98.8 | 100.0 |

## Location of neonatal death

The vast majority of early neonatal deaths occurred either in the labour ward, in another maternity unit ward or in the neonatal unit (Table 4.5). Less than one in ten deaths occurred in a paediatric centre.

Table 4.5: Location of neonatal death

| Place of death | n(%) |
|---|---|
| At home/in transit before arrival at a maternity unit | 3(1.9%) |
| Labour ward | 64(39.5%) |
| Neonatal unit | 68(42.0%) |
| Ward of the maternity unit | 16(9.9%) |
| Paediatric centre | 9(5.6%) |
| At home/in transit after delivery in a maternity unit | 2(1.2%) |

All 64 neonatal deaths that occurred in the labour ward occurred within 24 hours of delivery. These 64 deaths in the labour ward accounted for 60% (59.8%) of the 107 neonatal deaths that occurred in the first day. A further 23.4% (n=25) first day neonatal deaths occurred in a neonatal unit. As detailed in Table 4.4, the daily number of neonatal deaths was significantly lower once 24 hours had elapsed after delivery. Three quarters of the neonatal deaths after 1-6 completed days happened in a neonatal unit (n=43 of 53, 78.2%) and a further one in eight of these deaths (n=7, 12.7%) happening in a paediatric centre (Figure 4.2).

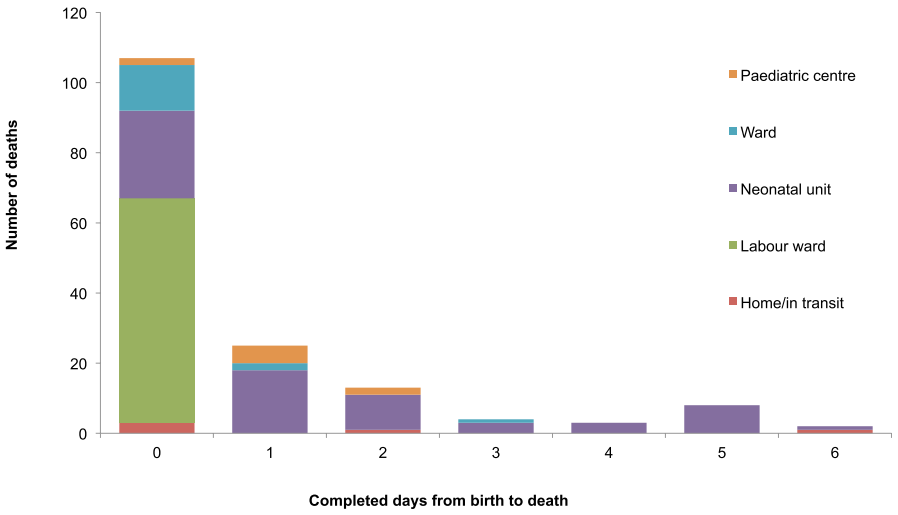


Figure 4.2: Place of neonatal death 0-6 complete days after birth

Table 4.6: Early neonatal main cause of death in 2011-2013, NPEC Classification System

| | 2011 N=138 | 2012 N=141 | 2013 N=162 |
|---|---|---|---|
| **Major congenital anomaly** | **71(51.4%)** | **68(48.2%)** | **92(56.8%)** |
| Central nervous system | 15 | 7 | 19 |
| Cardiovascular system | 8 | 7 | 9 |
| Respiratory system | 2 | 2 | 1 |
| Gastro-intestinal system | 2 | 2 | 2 |
| Musculo-skeletal system | 2 | 2 | 1 |
| Multiple anomalies | 8 | 12 | 17 |
| Chromosomal disorders | 20 | 17 | 25 |
| Metabolic disorders (in-born errors of metabolism) | 1 | 2 | - |
| Urinary tract | 6 | 13 | 9 |
| Other major congenital anomaly | 7 | 4 | 9 |
| **Pre-viable (<22 weeks)** | **-** | **1(0.7%)** | **1(0.6%)** |
| **Respiratory disorders** | **45(32.6%)** | **44(31.2%)** | **53(32.7%)** |
| Severe pulmonary immaturity | 39 | 29 | 32 |
| Surfactant deficiency lung disease | - | 9 | 14 |
| Pulmonary hypoplasia | 3 | 1 | 2 |
| Meconium aspiration syndrome | - | - | - |
| Primary persistent pulmonary hypertension | - | 1 | - |
| Chronic lung disease/bronchopulmonary dysplasia | - | - | - |
| Other respiratory disorder | 3 | 4 | 5 |
| **Gastro-intestinal disease** | **1(0.7%)** | **3(2.1%)** | **1(0.6%)** |
| Necrotising enterocolitis | 1 | 2 | 1 |
| Other gastro-intestinal disease | - | 1 | - |
| **Neurological disorder** | **7(5.1%)** | **14(9.9%)** | **10(6.2%)** |
| Hypoxic-ischaemic encephalopathy | 6 | 10 | 9 |
| Intraventricular/periventricular haemorrhage | - | 2 | 1 |
| Other neurological disorder | 1 | 2 | - |
| **Infection** | **6(4.3%)** | **4(2.8%)** | **3(1.9%)** |
| Sepsis | 4 | 2 | 1 |
| Pneumonia | - | 1 | 1 |
| Meningitis | - | - | - |
| Other infection | 2 | 1 | 1 |
| **Injury/Trauma** | **-** | **-** | **-** |
| **Other specific causes** | **2(1.4%)** | **3(2.1%)** | **1(0.6%)** |
| Malignancies/tumours | - | - | - |
| Other specific cause | 2 | 3 | 1 |
| **Sudden unexpected deaths** | **1(0.7%)** | **2(1.4%)** | **-** |
| Sudden infant death syndrome (SIDS) | 1 | 2 | - |
| Infant Deaths - Cause Unascertained | - | - | - |
| **Unexplained** | **5(3.6%)** | **2(1.4%)** | **1(0.6%)** |
| No antecedents or associated obstetric factors | - | 1 | - |
| Antecedents or associated obstetric factors present | - | - | - |
| Very limited information available | 5 | - | - |
| Pending post mortem or other investigation | - | 1 | 1 |

# 5. Perinatal deaths associated with intrapartum events

The investigation of perinatal deaths due to intrapartum events is valuable in assessing quality of care. These deaths are unexpected and include stillbirths alive at the onset of professional care in labour and neonatal deaths. Traditionally intrapartum deaths referred to babies who were alive at onset of labour but stillborn. The inclusion of neonatal deaths facilitates the assessment of all perinatal deaths that may have an intrapartum origin.

We reviewed perinatal deaths reported for 2011, 2012 and 2013 focusing on babies with a gestational age of at least 34 weeks and a birthweight of at least 2,500g and whose death was not due to major congenital anomaly, infection or placental abruption. In total, there were 35 such deaths in 2011-2013 suggesting a rate of 0.16 per 1,000 births (95% confidence interval: 0.11-0.22 per 1,000) or one in 6,148 births in Ireland. The 35 deaths occurred in 14 of the 20 maternity units operating in the country in 2011-2013. The unit-specific numbers are too small to draw conclusions regarding outliers.

Eleven deaths occurred in 2011 (six stillbirths and five early neonatal deaths), 13 occurred in 2012 (two stillbirths and 11 early neonatal deaths) and 11 occurred in 2013 (three stillbirths and eight early neonatal deaths). A post mortem was undertaken for all 11 deaths in 2013 and all were coroner cases. Details of the cases are provided in Table 5.1.

Table 5.1: Details of perinatal deaths in 2013 associated with intrapartum events

| Type of perinatal death | Gestational age (weeks) | Birthweight centile | Main antecedent or obstetric factor associated with the death | Neonatal cause of death |
|---|---|---|---|---|
| SB | 38 | 58th | Intra pulmonary haemorrhage | Not applicable |
| SB | 40 | 92nd | Placental maturation defect | Not applicable |
| SB | 40 | 51st | Unexplained cause[1] | Not applicable |
| ENND | 36 | 11th | No antenatal care, unattended home delivery, PROM, Chorioamnionitis | Respiratory Disorder |
| ENND | 35 | 93rd | Placental maturation defect | HIE |
| ENND | 40 | 2nd | Placental maturation defect | HIE |
| ENND | 34 | 52nd | Fetal vascular malperfusion | HIE |
| ENND | 40 | 69th | Fetal vascular malperfusion | HIE |
| ENND | 41 | 14th | Cord pathology | HIE |
| ENND | 40 | 20th | Intrapartum uterine rupture | HIE |
| ENND | Unknown | Unknown | Late booker, unattended home delivery, unexplained cause[2] | HIE |

Note: SB=Stillbirth; ENND=Early neonatal death; Unexplained cause[1]=some antecedents or associated obstetric factors; Unexplained cause2=pending results of coroner's post mortem; PROM=Premature rupture of membranes; HIE=hypoxic ischaemic encephalopathy

# 6. Late neonatal deaths: Specific findings

Data relating to 37 late neonatal deaths occurring in 2013 were reported to the NPEC for the purposes of this clinical audit. At the time of writing finalised figures for late neonatal deaths in 2013 were not yet published by the Central Statistics Office (CSO). In the five most recent years for which data are available, 2008-2012, the annual number of late neonatal deaths fluctuated between 29 and 41 with no discernible trend. For the year 2012, there were 40 late neonatal deaths according to the published CSO figures and 40 late neonatal deaths were reported to the NPEC. Thus, the numbers reported to the NPEC are consistent with the CSO figures for recent years. However, maternity hospitals may not be notified of the late neonatal death of a baby delivered in their unit if the baby was transferred to a paediatric unit or discharged home. The NPEC is working with colleagues in the relevant hospitals (maternity and paediatric) and in the National Office of Clinical Audit to address this issue.

Given the notification issue and the limited number of late neonatal deaths reported, this section of the report provides a brief summary of the submitted data as well as the detailed listing of the main cause of the 37 deaths according to the NPEC Classification System.

Similar to early neonatal deaths, approximately half of late neonatal deaths were due to major congenital anomaly (n=18, 48.6%). The next most common causes were neurological disorders (n=7, 18.9%), respiratory disorders (n=5, 13.5%) and sudden infant death syndrome (n=4, 10.8%). The main cause of one late neonatal death was unexplained pending post mortem or other investigation.
Table 6.1 describes a range of characteristics of the babies who died in the late neonatal period. Most of the babies who died in the late neonatal period were male. This fluctuates from year to year. There were similar proportions of male (n=18, 45.0%) and female (n=22, 55.0%) babies among those who died in the late neonatal period in 2012 whereas in 2011 three quarters of the babies were male (n=26 of 35, 74.3%).

Half of the babies who died in the late neonatal period in 2013 were born by spontaneous vaginal delivery and 43% were delivered by caesarean section. Most had a gestational age of at least 37 weeks at birth but almost half (n=17, 45.9%) had a birthweight less than 2,500 grams. One in five of the babies were small for gestational age (SGA; <10th centile).

Previous reports have shown that the proportion of late neonatal deaths decreases across the second, third and fourth weeks of life. This was not the case in 2013 as 40.5%, 24.3% and 35.1% died in weeks two, three and four, respectively (Table 6.1).

Most late neonatal deaths in 2013 occurred in the neonatal unit and one in four died in a paediatric centre.

Table 6.1: Characteristics of late neonatal deaths, 2012-2013

| | 2012, N=40 | 2013, N=37 |
|---|---|---|
| **Infant sex** | | |
| Male | 18 (45.0) | 22 (59.5) |
| Female | 22 (55.0) | 15 (40.5) |
| **Mode of delivery** | | |
| Spontaneous vertex delivery | 22 (5.0) | 18 (48.6) |
| Pre-labour caesarean section | 10 (25.0) | 9 (24.3) |
| Caesarean section after onset of labour | 4 (10.0) | 7 (18.9) |
| Forceps | 1 (2.5) | - |
| Assisted breech | 2 (5.0) | 2 (5.4) |
| Ventouse | 1 (2.5) | 1 (2.7) |
| **Gestational age at delivery** | | |
| 22-27 weeks | 15 (37.5) | 11 (29.7) |
| 28-31 weeks | 1 (2.5) | 3 (8.1) |
| 32-36 weeks | 6 (15.0) | 2 (5.4) |
| 37-41 weeks | 18 (45.0) | 21 (56.8) |
| **Birthweight** | | |
| 500<1000g | 16 (40.0) | 11 (29.7) |
| 1000<1500g | - | 1 (2.7) |
| 1500<2000g | 5 (12.5) | 3 (8.1) |
| 2000<2500g | 6 (15.0) | 2 (5.4) |
| 2500<3000g | 5 (12.5) | 7 (18.9) |
| 3000<3500g | 4 (10.0) | 7 (18.9) |
| 3500<4000g | 1 (2.5) | 5 (13.5) |
| 4000g+ | 3 (7.5) | 1 (2.7) |
| **Customised birthweight centile category** | | |
| Zero | 10 (25.0) | 2 (5.4) |
| <3rd | 13 (32.5) | 3 (8.1) |
| <10th | 17 (42.5) | 8 (21.6) |
| 10-49th | 13 (32.5) | 16 (43.2) |
| 50-89th | 6 (15.0) | 11 (29.7) |
| 90th+ | 4 (10.0) | 2 (5.4) |
| **Timing of death** | | |
| 2nd week of life | 23 (57.5) | 15 (40.5) |
| 3rd week of life | 10 (25.0) | 9 (24.3) |
| 4th week of life | 7 (17.5) | 13 (35.1) |
| **Location of death** | | |
| Home (after delivery in a maternity unit) | 6 (15.0) | 5 (13.5) |
| Ward of the maternity unit | 1 (2.5) | 1 (2.7) |
| Neonatal unit | 18 (45.0) | 21 (56.8) |
| In transit home | 1 (2.5) | - |
| Paediatric centre | 14 (35.0) | 10 (27.0) |

Table 6.2: Late neonatal main cause of death in 2011-2013, NPEC Classification System

| | 2011 N=35 | 2012 N=40 | 2013 N=37 |
|---|---|---|---|
| **Major congenital anomaly** | **20(57.1%)** | **15(37.5%)** | **18(48.6%)** |
| **Central nervous system** | **2** | **2** | **2** |
| Cardiovascular system | 5 | 5 | 4 |
| Respiratory system | 1 | 1 | - |
| Gastro-intestinal system | 1 | - | 1 |
| Musculo-skeletal system | 1 | - | 1 |
| Multiple anomalies | 1 | 2 | 3 |
| Chromosomal disorders | 6 | 4 | 4 |
| Metabolic disorders | - | - | 1 |
| Urinary tract | - | - | 1 |
| Other major congenital anomaly | 3 | 1 | 1 |
| **Pre-viable (<22 weeks)** | **-** | **-** | **-** |
| **Respiratory disorders** | **5(14.3%)** | **9(22.5%)** | **5(13.5%)** |
| Severe pulmonary immaturity | 5 | 5 | 4 |
| Surfactant deficiency lung disease | - | 1 | - |
| Pulmonary hypoplasia | - | - | - |
| Meconium aspiration syndrome | - | - | - |
| Primary persistent pulmonary hypertension | - | - | - |
| Chronic lung disease/bronchopulmonary dysplasia | - | - | 1 |
| Other respiratory disorder | - | 3 | - |
| **Gastro-intestinal disease** | **2(5.7%)** | **6(15.0%)** | **1(2.7%)** |
| Necrotising enterocolitis | 2 | 5 | 1 |
| Other gastro-intestinal disease | - | 1 | - |
| **Neurological disorder** | **2(5.7%)** | **1(2.5%)** | **7(18.9%)** |
| Hypoxic-ischaemic encephalopathy | 1 | - | 3 |
| Intraventricular/periventricular haemorrhage | - | - | 4 |
| Other neurological disorder | 1 | 1 | - |
| **Infection** | **4(11.4%)** | **4(10.0%)** | **1(2.7%)** |
| Sepsis | 4 | 3 | 1 |
| Pneumonia | - | - | - |
| Meningitis | - | - | - |
| Other infection | - | 1 | - |
| **Injury/Trauma** | **-** | **-** | **-** |
| **Other specific causes** | **-** | **-** | **-** |
| Malignancies/tumours | - | - | - |
| Other specific cause | - | - | - |
| **Sudden unexpected deaths** | **-** | **3(7.5%)** | **4(10.8%)** |
| Sudden infant death syndrome (SIDS) | - | 3 | 4 |
| Infant Deaths - Cause Unascertained | - | - | - |
| **Unexplained** | **2(5.7%)** | **2(5.0%)** | **1(2.7%)** |
| No antecedents or associated obstetric factors | - | - | - |
| Antecedents or associated obstetric factors present | - | - | - |
| Very limited information available | 2 | 2 | - |
| Pending post mortem or other investigation | - | - | 1 |

# 7. Early neonatal deaths with a birthweight <500g and a gestational age at delivery <24 weeks

While not included in the calculation of perinatal mortality rates, we ask for notification of deaths in the early neonatal period of babies born before 24 weeks gestation and weighing less than 500g. For 2013, 41 such deaths were reported by six maternity units. These maternity units accounted for almost 60% (58.9%) of births in Irish maternity units in 2013. Using this proportion would give a national estimate for 2013 of 70 early neonatal deaths of babies born before 24 weeks gestation with a birthweight less than 500g.

Using the NPEC Neonatal Classification System, the assigned cause of death was pre-viable (<22 weeks) for 25 cases (61.0%) and severe pulmonary immaturity for the other 16 cases (39.0%). Based on the NPEC Maternal and Fetal Classification System, the antecedent or associated obstetric factors in these 41 early neonatal deaths were spontaneous premature labour (n=25, 61.0%), ascending infection (n=12, 29.3%), specific placental conditions (n=3, 7.3%) and premature rupture of membranes (n=1, 2.4%).

The birthweights of the babies were in the range 205-495g and their gestation at delivery was 17-23 weeks. The evidence of fetal growth restriction was limited as indicated by the customised birthweight centiles calculated for 38 of the 41 babies. Six (15.8%) were small-for-gestational-age (SGA; <10th centile) and four (10.5%) severely SGA (<3rd centile). However, close to 90% (n=32 of 38, 84.2%) were above the 10th centile.

All died within 24 hours of being delivered, most commonly in the labour ward (n=29, 70.7%) but in some cases in another ward of the maternity unit (n=12, 29.3%). For 33 of the 41 babies (80.5%), spontaneous respiratory activity was absent or ineffective at five minutes following delivery and for 30 babies (73.2%) the heart rate was persistently less than 100 beats per minute. Only one case was offered active resuscitation in the delivery room and none were admitted to the neonatal unit.

An autopsy was performed in six cases (14.6%) and an autopsy was offered in 24 of the other 35 cases. Placental histology examination was conducted following all 41 deaths.

# Appendix A: Perinatal Mortality Group members

**Ms Bridget Boyd,** Assistant Director of Midwifery, Coombe Women & Infants University Hospital
*Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE*

**Dr Gerry Burke,** Consultant Obstetrician/Gynaecologist, Midwestern Region Maternity Hospital
*Nominated by the Institute of Obstetricians & Gynaecologists, RCPI*

**Dr David Corcoran,** Consultant Neonatologist, Rotunda Hospital
*Nominated by the Faculty of Paediatrics*

**Dr Elizabeth Dunn,** Consultant Obstetrician/Gynaecologist, Wexford General Hospital
*Nominated by the Institute of Obstetricians & Gynaecologists, RCPI*

**Dr Siobhan Gormally,** Consultant Paediatrician Our Lady of Lourdes Hospital
*Nominated by Martin White of the Faculty of Paediatrics, RCPI*

**Ms Oonagh McDermott,** Assistant Director of Midwifery, Sligo General Hospital
*Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE*

**Dr Eoghan Mooney,** Consultant Pathologist, National Maternity Hospital
*Nominated by the Faculty of Pathology, RCPI*

**Dr Keelin O'Donoghue,** Consultant Obstetrician/Gynaecologist, Cork University Maternity Hospital
*Nominated by the Institute of Obstetricians & Gynaecologists, RCPI*

**Ms May Quirke,** Assistant Director of Midwifery, Tralee General Hospital
*Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE*

**Ms Ann Rath,** Clinical Midwife Manager 3, National Maternity Hospital
*Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE*

**Dr Anne Twomey,** Consultant Neonatologist, National Maternity Hospital
*Nominated by the Faculty of Paediatrics, RCPI*

**Ms Patricia Williamson,** Assistant Director of Midwifery, Rotunda Hospital
*Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE*

**Prof Richard Greene,** Consultant Obstetrician/Gynaecologist, Cork University Maternity Hospital
*Chair, Director of the National Perinatal Epidemiology Centre*

**Ms Edel Manning,** Research Midwife, National Perinatal Epidemiology Centre
*Perinatal Mortality Project Manager*

**Mr Paul Corcoran PhD,** Senior Lecturer in Perinatal Epidemiology,
*National Perinatal Epidemiology Centre National Perinatal Epidemiology Centre contributor*

**Ms Sarah Meaney,** Health Promotion Research Officer, National Perinatal Epidemiology Centre
*National Perinatal Epidemiology Centre contributor*

# Appendix B: Endorsment of Perinatal Mortality 2013

NOCA National Office of Clinical Audit

Professor Richard A. Greene
Director
National Perinatal Epidemiology Centre
5th Floor, Cork University Maternity Hospital
Wilton
Cork

01st October 2015

**Perinatal Mortality in Ireland, Annual Report 2013**

Dear Professor Greene,

I acknowledge receipt of NPEC's Perinatal Mortality in Ireland, Annual Report 2013 and confirm following circulation to the NOCA Governance Board and feedback garnered from our membership, we are delighted to endorse this report.

You and colleagues Ms Edel Manning, Dr Paul Corcoran, Ms Sarah Meaney and Ms Linda Drummond are to be congratulated for the quality of the report and manner in which you continue to engage with maternity services to maintain this work.

We welcome your recommendations, in particular the proposal that a Confidential Enquiry for Stillbirth and Neonatal deaths be established in order to enhance the learning and improve care. As you are aware our governance requires retrospective in-depth review of audit findings outside the norm, your recommendation to establish a confidential enquiry certainly would align to this very well.

Equally we fully support NPEC's recommendation to establish a formal national perinatal pathology service, in association with the Faculty of Pathology which in turn will allow greater research and learning to the benefit of mothers and babies in Ireland.

As you are aware the NOCA Board is working to convene a specialist paediatric governance group which we hope may go some way to support NPEC's efforts to bring about a structured notification system to improve inter hospital communication when neonatal or infant deaths occur in a tertiary or paediatric centres.

On behalf of all our associate NOCA Audit streams, we continue to highlight requirement for protected time of clinical staff to collect, monitor and adequately interpret audit data at hospital level.

Finally, we welcome your efforts to accelerate the reporting process and look forward to receiving the 2014 Perinatal Mortality Audit data early next year.

Yours sincerely,

Sean Tierney

**Professor Sean Tierney**
**Chairman**
**National Office of Clinical Audit**

National Office of Clinical Audit, 4th Floor, 121 St. Stephen's Green, Dublin 2 Tel: 4028577

Tús Áite do Shábháilteacht Othar
Patient Safety First

# Appendix C: National Office of Clinical Audit Governance Board endorsement of Perinatal Mortality in Ireland Annual Report 2013

| Hospital | Co-ordinators | Additional contributors |
|---|---|---|
| **Cavan General Hospital** | Dr Rukhsana Majeed, Ms Evelyn McAdam | Dr Salah Aziz, Ms Margaret Mulvany, Ms Karen Malocca |
| **Coombe Women and Infants University Hospital** | Dr Gillian Ryan, Dr Gbenga Oluyede | Dr Sharon Sheehan |
| **Cork University Maternity Hospital** | Dr Keelin O'Donoghue, Ms Siobhan Bourke, Dr Brendan Murphy | |
| **Kerry General Hospital, Tralee** | Ms Claire Fleming Kelliher, Ms Mary Stack Courtney | |
| **Letterkenny General Hospital** | Ms Raphael Dalton, Ms Mary Doherty, Ms Geraldine Hanley, Ms Mary Lynch | Ms Evelyn Smith |
| **Mayo General Hospital, Castlebar** | Ms Pauline Corcoran, Ms Diane Brady | Dr Hilary Ikele, Dr Meabh Ní Bhuinneain |
| **Midland Regional Hospital, Mullingar** | Ms Marie Corbett | |
| **Midland Regional Hospital, Portlaoise** | Ms Emma Mullins, Ms Ita Kinsella, | |
| **Mid-Western Regional Maternity Hospital, Limerick** | Ms Sandra O'Connor, Ms Margo Dunworth | |
| **Mount Carmel Hospital, Dublin** | Ms Catherine Halloran Ms Felicity Doddy | Dr Valerie Donnelly |
| **National Maternity Hospital, Dublin** | Ms Fionnuala Byrne | Dr Eoghan Mooney, Dr Anne Twomey |
| **Our Lady of Lourdes Hospital, Drogheda** | Ms Anne Keating | Dr Seosamh Ó Cóigligh |
| **Portiuncula Hospital, Ballinasloe** | Ms Mairead Hynes, Ms Karen Leonard, Ms Priscilla Neilan | |
| **Rotunda Hospital, Dublin** | Ms Ruth Ritchie | Dr Sam Coulter Smith |
| **Sligo Regional Hospital** | Ms Juliana Henry, Ms Oonagh Mc Dermott | Dr Heather Langan |
| **South Tipperary General Hospital, Clonmel** | Ms Siobhan Kavanagh | |
| **St Luke's Hospital, Kilkenny** | Ms Connie McDonagh | |
| **University Hospital Galway** | Ms Marie Hession | |
| **Waterford Regional Hospital** | Ms Margaret Coe, Ms Emer Denn | Ms Paula Curtain |
| **Wexford General Hospital** | Ms Helen McLoughlin | |

# Appendix D: Perinatal Death Notification Form 2013

NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

**For NPEC Office use only:**
**CODE FOR CASE**

**PLACE OF DEATH:**

## PERINATAL DEATH NOTIFICATION FORM

## 2013

**CHOOSE Type of Case** *(TICK)*

☐ **STILLBIRTH:** *A baby delivered without signs of life* from 24 weeks' gestation and/or with a birth weight of ≥ 500g.

*If the birth occurred unattended and there was no lung aeration seen at Post Mortem (PM) and no other circumstantial evidence of life at birth, it should be assumed that the baby was stillborn.

**OR**

☐ **EARLY NEONATAL DEATH:** *Death of a live born baby occurring before 7 completed days after birth.*

**OR**

☐ **LATE NEONATAL DEATH:** *Death of a live born baby occurring from the 7th day and before 28 completed days after birth.*

* For the purpose of reporting, a 'live born' baby is defined as any baby born with evidence of life such as breathing movements, presence of a heart beat, pulsation of the cord or definite movement of voluntary muscles.

**If a baby born at <22 completed weeks is being registered as a neonatal death, please report same to NPEC.**

The National Perinatal Epidemiology Centre is sincerely grateful for your contribution to this audit.

Guidance for completing this form, with specific reference to Sections 11, 12 and 13 on Cause of Death, is outlined in the accompanying reference manual.

The National Perinatal Epidemiology Centre also acknowledges with thanks the Centre for Maternal and Child Enquiry (CMACE) UK for permission to modify and use its Perinatal Mortality Notification Proforma for use in the Irish context.

1

## SECTION 1. WOMANS' DETAILS

**1.1. Mother's age** ☐☐

**1.2. Ethnic group:**

☐ White - Irish ☐ Irish Traveller

☐ Any other White background ☐ Please specify country of origin_____

☐ Asian or Asian Irish ☐ Black or Black Irish

☐ Other including mixed ethnic backgrounds: Please specify _____

☐ Not recorded

**1.3. What was the woman's occupation at booking?**

_____

**1.4. What was the occupation of the woman's partner at booking?**

_____

**1.5. Level of education completed by this woman:**

☐ Primary or less ☐ Secondary ☐ Third Level ☐ Unknown

**1.6. Height at booking (round up to the nearest cm):** ☐☐☐

**1.7. Weight at booking (round up to the nearest kg):** ☐☐☐

If weight is unavailable, was there evidence that the woman was too heavy for hospital scales? ☐ Yes ☐ No

**1.8. Body Mass Index at booking (BMI):** ☐☐.☐

**1.9.a. Did the woman smoke at booking?** ☐ Yes, specify quantity smoked per day_____

☐ No ☐ Unknown

**1.9.b. Did she give up smoking during pregnancy?** ☐ Yes ☐ No ☐ Unknown ☐ N/A

**1.10. Is there documented history of alcohol abuse?**

☐ None recorded ☐ Prior to this pregnancy ☐ During this pregnancy

**1.11. Is there documented history of drug abuse or attendance at a drug rehabilitation unit?**

☐ None recorded ☐ Prior to this pregnancy ☐ During this pregnancy

## SECTION 2. PREVIOUS PREGNANCIES

**2.1. Did the woman have any previous pregnancies?** *If yes, please complete questions 2.2-2.4* ☐ Yes ☐ No

**2.2. No. of completed pregnancies ≥24 weeks and or with a birth weight ≥ 500g (all live and stillbirths):** ☐☐

**2.3. No. of pregnancies <24 weeks and with a birth weight < 500g:** ☐☐

**2.4. Were there any previous pregnancy problems?** *If yes, please tick all that apply below* ☐ Yes ☐ No

☐ Three or more miscarriages ☐ Pre-term birth or mid trimester loss ☐ Stillbirth, *please specify number* ☐

☐ Infant requiring intensive care ☐ Baby with congenital anomaly ☐ Neonatal death, *please specify number* ☐

☐ Previous caesarean section ☐ Placenta praevia ☐ Placental abruption

☐ Pre-eclampsia (hypertension & proteinuria) ☐ Post-partum haemorrhage requiring transfusion

☐ Other, please specify_____ ☐ Unknown

## SECTION 3. PREVIOUS MEDICAL HISTORY

**3.1. Were there any pre-existing medical problems?** *If yes, please tick all that apply below* ☐ Yes ☐ No ☐ Unknown

☐ Cardiac disease (congenital or acquired) ☐ Epilepsy

☐ Endocrine disorders e.g. hypo or hyperthyroidism ☐ Renal disease

☐ Haematological disorders e.g. sickle cell disease ☐ Psychiatric disorders

☐ Inflammatory disorders e.g. inflammatory bowel disease ☐ Hypertension

☐ Diabetes ☐ Other, please specify _____

## SECTION 4. THIS PREGNANCY

**4.1. Final Estimated Date of Delivery (EDD):** ☐☐/☐☐/☐☐ ☐ Unknown

Use best estimate *(ultrasound scan or date of last menstrual period)* based on a 40 week gestation, or the final date agreed in the notes.

**4.2. Was this a multiple pregnancy at the onset of pregnancy?** ☐ Yes ☐ No

**4.3. Was this pregnancy a result of infertility treatment?** ☐ Yes ☐ No ☐ Unknown

If yes, please specify method of fertility treatment _____

**4.4 Gestation at first booking appointment:** ☐☐ weeks + ☐ days ☐ Not booked ☐ Unknown

**4.5 Intended place of delivery at booking:** Name of unit _____

*Please specify the type of unit*

☐ Obstetric Unit ☐ Alongside Midwifery Unit ☐ Home ☐ Unbooked

**4.6 What was the intended type of delivery care at booking?**

☐ Obstetric-Led Care ☐ Midwifery-Led Care ☐ Self-Employed Community Midwife

☐ Home c/o Hospital DOMINO Scheme

## SECTION 5. DELIVERY

**5.1. Onset of labour:**

☐ Spontaneous ☐ Induced ☐ Never in labour

**5.2. Intended place of delivery at onset of labour:** Name of unit _____

*Please specify the type of unit*

☐ Obstetric Unit ☐ Alongside Midwifery Unit ☐ Home

**5.3. What was the intended type of care at onset of labour?**

☐ Obstetric-Led Care ☐ Midwifery-Led Care ☐ Self-Employed Community Midwife

☐ Home c/o Hospital DOMINO Scheme

**5.4. Was the intended mode of delivery a planned caesarean section?** ☐ Yes ☐ No

**5.5. Place of delivery:** Name of unit _____

*Please specify the type of unit*

☐ Obstetric Unit ☐ Alongside Midwifery Unit ☐ Home

**5.6. What was the type of care at delivery?**

☐ Obstetric-Led Care ☐ Midwifery -Led Care ☐ Born Before Arrival (BBA) - Unattended

☐ Self-Employed Community Midwife ☐ Home c/o Hospital DOMINO Scheme

**5.7. Date and time of delivery/birth:** **Date:** ☐☐/☐☐/☐☐ **Time:** ☐☐:☐☐

**5.8. What was the presentation *at full dilation*?**

☐ Vertex ☐ Breech ☐ Compound *(includes transverse and shoulder presentations)* ☐ Brow ☐ Face

**5.9. What was the presentation *at delivery*?**

☐ Vertex ☐ Breech ☐ Compound *(includes transverse and shoulder presentations)* ☐ Brow ☐ Face

**5.10. What was the mode of delivery?** (Please tick all that apply)

☐ Spontaneous Vaginal ☐ Ventouse ☐ Lift-Out Forceps ☐ Mid-Cavity Forceps ☐ Rotational Forceps

☐ Assisted Breech delivery ☐ Pre-Labour Caesarean Section ☐ Caesarean Section After Onset of Labour

### CAESAREAN SECTIONS ONLY

**5.11. What was the type of *or* indication for Caesarean Section?**

☐ Elective - At a time to suit woman or maternity team ☐ Urgent - Maternal or fetal compromise which is not immediately life threatening

☐ Emergency - Immediate threat to life of woman or fetus ☐ Failed instrumental delivery

## SECTION 6. ALL BABY OUTCOME

**6.1. Sex of fetus/baby:** ☐ Male ☐ Female ☐ Indeterminate

**6.2. Number of fetuses/babies in this delivery:** *(all identifiable including papyraceous)* ☐

**Birth order of this fetus/baby:**

☐ Singleton

☐ Twin 1 ☐ Twin 2

☐ Triplet 1 ☐ Triplet 2 ☐ Triplet 3

☐ Other multiple birth pregnancy, please specify_____ Birth Order ☐

**6.3. If from a multiple delivery, what was the chorionicity?** *Please tick all that apply*

☐ Dichorionic diamniotic ☐ Monochorionic diamniotic ☐ Monochorionic monoamniotic ☐ Trichorionic ☐ Not known

**6.4. Birth weight (kg):** ☐.☐☐☐

**6.5. Gestation at delivery:** ☐☐ weeks + ☐ days ☐ Unknown

**6.6. Was this a termination of pregnancy?** ☐ Yes ☐ No

*Please refer to the reference manual, page 2*

**6.7. Was a local hospital review of this case undertaken?** ☐ Yes ☐ No

## SECTION 7. MATERNAL OUTCOME

**7.1. Admission to HDU:** ☐ Yes ☐ No

**7.2. Admission to ICU:** ☐ Yes ☐ No

**7.3. Maternal Death:** ☐ Yes ☐ No

## SECTION 8. STILLBIRTH (If not a stillbirth, please go to Section 9)

**8.1. At what gestation was death confirmed to have occurred?** ☐☐ weeks + ☐ days

If known, what date was death confirmed? ☐☐/☐☐/☐☐

**8.2. Was the baby alive at *onset of care* in labour?**

☐ Yes ☐ No ☐ Never In Labour ☐ Unattended ☐ Unknown

## SECTION 9. NEONATAL DEATH ONLY

**9.1. Was spontaneous respiratory activity absent or ineffective at 5 minutes?** ☐ Yes ☐ No

If a baby is receiving any artificial ventilation at 5 minutes, the assumption is absent/ineffective activity: a 0 Apgar score indicates absent activity.

**9.2. Was the heart rate persistently <100bpm? ( i.e. heart rate never rose above 100bpm before death)**

☐ Persistently <100bpm ☐ Rose above 100bpm

**9.3. Was the baby offered *active resuscitation in the delivery room?** ☐ Yes ☐ No

(*active resuscitation includes BMV, PPV, intubation, cardiac massage)

**9.4. Was the baby admitted to a neonatal unit?** (Includes SCBU and ICU) ☐ Yes ☐ No

**9.5. Was the baby transferred to another unit after birth?** ☐ Yes ☐ No

**9.6. Date and Time of Death:** **Date** ☐☐/☐☐/☐☐ **Time** ☐☐:☐☐

**9.7. Place of Death*:** ☐ Labour Ward ☐ Neonatal Unit ☐ Ward ☐ In Transit ☐ Paediatric Centre ☐ Home

Name of unit:_____

*This question refers to where the baby actually died, e.g. 'ICU, 'at home' or 'in transit'.
Babies are deemed to have died 'at home' if there are no signs of life documented in the home even if resuscitation is attempted.
A baby is deemed to have died 'in transit' if signs of life are documented prior to transfer but the baby was either declared dead on arrival to the hospital or showed no subsequent signs of life in the hospital, despite attempted resuscitation..

## SECTION 10. POST-MORTEM

**10.1. Was this a coroner's case?** *If yes, please complete question 10.2.* ☐ Yes ☐ No

**10.2. Has the post-mortem report been received from the coroner's office?** ☐ Yes ☐ No

*If no, please complete question 10.3.*

**10.3. Please specify which coroner's jurisdiction this case was assigned to:** _____

**10.4. Was a post-mortem performed?** ☐ Yes ☐ No

*If no, please complete question 10.5.*

**10.5. Was a post-mortem offered?** ☐ Yes ☐ No

**10.6. Were any of the following procedures carried out after death?**

*Please tick all that apply*

☐ MRI ☐ X-Ray ☐ CT ☐ External Examination

**10.7. Was the placenta sent for histology?** ☐ Yes ☐ No

## SECTION 11. CAUSE OF DEATH AND ASSOCIATED FACTORS - STILLBIRTH & NEONATAL DEATH

**11. Please TICK ALL the maternal or fetal conditions that were present during pregnancy or were associated with the death.** ***PLEASE REFER TO THE REFERENCE MANUAL.***

### 11.1.1. MAJOR CONGENITAL ANOMALY:

☐ Central nervous system ☐ Cardiovascular system ☐ Respiratory system ☐ Gastro-intestinal system

☐ Musculo-skeletal anomalies ☐ Multiple anomalies ☐ Urinary tract ☐ Metabolic diseases

☐ Other major congenital anomaly, please specify _____

☐ Chromosomal disorder*, please specify _____

*** In the event of a chromosomal disorder how was the diagnosis made?**

☐ Clinically ☐ Cytogenetic analysis * ☐ Ultrasound

**See reference manual, page 2*

### 11.1.2. HYPERTENSIVE DISORDERS OF PREGNANCY:

☐ Pregnancy induced hypertension ☐ Pre-eclampsia ☐ HELLP syndrome ☐ Eclampsia

### 11.1.3. ANTEPARTUM or INTRAPARTUM HAEMORRHAGE:

☐ Praevia ☐ Abruption ☐ Cause uncertain

### 11.1.4. MECHANICAL:

***Cord compression***: ☐ Prolapse cord ☐ Cord around neck ☐ Other cord entanglement or knot

***Uterine rupture***: ☐ Before labour ☐ During labour

***Mal-presentation***: ☐ Breech ☐ Face ☐ Compound

☐ Transverse ☐ Other, please specify _____

***Shoulder dystocia:*** ☐

### 11.1.5. MATERNAL DISORDER:

☐ Pre-existing hypertensive disease ☐ Diabetes ☐ Other endocrine conditions (excluding diabetes)

☐ Thrombophilias ☐ Obstetric cholestasis ☐ Uterine anomalies

☐ Connective tissue disorders, please specify_____

☐ Other, please specify_____

### 11.1.6. INFECTION: (confirmed by microbiology/placental histology)

***Maternal infection:*** ☐ Bacterial ☐ Syphilis ☐ Viral diseases

☐ Protozoal ☐ Group B Streptococcus

☐ Other, please specify organism _____

***Ascending infection:***

☐ Chorioamnionitis ☐ Other, please specify _____

### 11.1.7. SPECIFIC FETAL CONDITIONS:

☐ Twin-twin transfusion ☐ Feto-maternal haemorrhage ☐ Non-immune hydrops ☐ Iso-immunisation

☐ Other, please specify_____

**11.1.8. SPECIFIC PLACENTAL CONDITIONS:**

☐ No abnormal histology reported

☐ Vasa praevia ☐ Velamentous insertion ☐ Massive perivillous fibrin deposition

☐ Placental infarction → Please specify approximate percentage involved _____

☐ Chorioamnionitis → ☐ Mild ☐ Moderate ☐ Severe

☐ Fetal vasculitis → ☐ Arterial ☐ Venous ☐ Both

☐ Retroplacental haemorrhage → Please specify approximate percentage of maternal surface involved _____

☐ Thrombosis in fetal circulation → Please specify if arterial or venous _____

☐ Villitis → ☐ Mild ☐ Moderate ☐ Severe

☐ Other, please specify_____

**11.1.9. INTRA-UTERINE GROWTH RESTRICTION DIAGNOSIS MADE: YES ☐**

What was this based on? *Please tick all that apply*

☐ Suspected antenatally ☐ Observed at delivery ☐ Observed at post-mortem

**11.1.10. ASSOCIATED OBSTETRIC FACTORS:** *Please tick all that apply*

***Birth trauma*** ☐ Intracranial haemorrhage ☐ Subgaleal haematoma

☐ Fracture, please specify_____

☐ Other, please specify_____

***Intrapartum fetal blood sample result < 7.25*** ☐ Yes ☐ No

☐ Polyhydramnios ☐ Oligohydramnios ☐ Premature rupture of membranes

☐ Prolonged rupture of membranes (> 24hours) ☐ Amniocentesis

☐ Spontaneous premature labour ☐ Other, please specify_____

**11.1.11. NO ANTECEDENT OR ASSOCIATED OBSTETRIC FACTORS**: ☐

**11.1.12. UNCLASSIFIED:** *Please use this category as sparingly as possible* ☐

## SECTION 12. MAIN CAUSE OF DEATH: STILL BIRTH & NEONATAL DEATHS

**12.1. Which condition, indicated in Section 11 as being present, was the MAIN condition or sentinel event causing or associated with the death.** *Please refer to the post-mortem report. In the absence of a post-mortem report, please refer to the death certificate.*

*(NB "non-MAIN" conditions are best described as the "Other clinically relevant maternal or fetal conditions/ factors that were associated with but not necessarily causing the death").*

**12.2. Was the cause of death question completed using a placental histology report or a post-mortem report?**

*Please tick all that apply*

☐ Post Mortem ☐ Placental Histology ☐ Both ☐ Neither

## SECTION 13. NEONATAL DEATH ONLY: NEONATAL CONDITIONS ASSOCIATED WITH THE DEATH

**13.1. Please TICK ALL the neonatal conditions causing and associated with the death.**
***PLEASE REFER TO THE REFERENCE MANUAL.***

### 13.1.1. MAJOR CONGENITAL ANOMALY:

☐ Central nervous system ☐ Cardiovascular system ☐ Respiratory system ☐ Gastro-intestinal system

☐ Musculo-skeletal anomalies ☐ Multiple anomalies ☐ Urinary tract ☐ Metabolic diseases

☐ Other major malformation, please specify _____

☐ Chromosomal disorder*, please specify _____

*** In the event of a chromosomal disorder how was the diagnosis made?**

☐ Clinically ☐ Cytogenetic analysis * ☐ Ultrasound
**See reference manual*

### 13.1.2. PRE-VIABLE: (less than 22 weeks) ☐

### 13.1.3. RESPIRATORY DISORDERS:

☐ Severe pulmonary immaturity ☐ Surfactant deficiency lung disease ☐ Pulmonary hypoplasia ☐ Meconium aspiration syndrome

☐ Primary persistent pulm. hypertension ☐ Chronic lung disease / Bronchopulmonary dysplasia (BPD)

☐ Other (includes pulmonary haemorrhage), please specify_____

### 13.1.4. GASTRO-INTESTINAL DISEASE:

☐ Necrotising enterocolitis (NEC) ☐ Other, please specify _____

### 13.1.5. NEUROLOGICAL DISORDER:

☐ Hypoxic-ischaemic encephalopathy (HIE)

☐ * Intraventricular / Periventricular haemorrhage, please specify highest grade (0 – 4) ☐ *

☐ Hydrocephalus*, please tick all that apply:

* ☐ Congenital ☐ Acquired ☐ Communicating ☐ Obstructive ☐ Other_____

☐ Other, please specify_____

### 13.1.6. INFECTION:

☐ Generalised (sepsis) ☐ Pneumonia ☐ Meningitis

☐ Other, specify _____

### 13.1.7. INJURY / TRAUMA: (Postnatal) ☐

Please specify_____

**13.1.8. OTHER SPECIFIC CAUSES:**

☐ Malignancies / Tumours ☐ In-born errors of metabolism, please specify _____

☐ Specific conditions, please specify_____

**13.1.9. SUDDEN UNEXPECTED DEATHS:**

☐ Sudden Infant Death Syndrome (SIDS) ☐ Infant death – Cause unascertained

**13.1.10. UNCLASSIFIED:** (Use this category as sparingly as possible) ☐

**13.2. Which condition, indicated in Section 13.1 as being present, was the MAIN condition causing or associated with the death.** *Please refer to the post-mortem report. In the absence of a post-mortem report, please refer to the death certificate.*

*(NB "non-MAIN" conditions are best described as the "Other clinically relevant maternal or fetal conditions/ factors that were associated with but not necessarily causing the death").*

**13.3. Was the cause of death question completed using a placental histology or a post-mortem report?**

*Please tick all that apply*

☐ Post Mortem ☐ Placental Histology ☐ Both ☐ Neither

## SECTION 14. DETAILS OF REPORTING UNIT (Please print)

**14.1. Name of reporting unit:** _____

**14.2. Completed by**

**Name:** _____

**Staff Grade:** _____

**Work address:** _____

_____

**Telephone Number:** _____

**E-mail Address:**_____

**Date of Notification:** ☐☐/☐☐/☐☐

**Thank you very much for taking the time to complete this form**

# Appendix E: Cause of Death Guidance and Definitions

**Guidance and Definitions for Completion of Section 11 & 12**
**STILLBIRTH AND NEONATAL DEATH**

| DEFINITION OF TERMS | Subcategory |
|---|---|
| **1. MAJOR CONGENITAL ANOMALY.** Any genetic or structural defect arising at conception or during embryogenesis incompatible with life or potentially treatable but causing death | Central nervous system<br>Cardiovascular system<br>Respiratory system<br>Gastro-intestinal system<br>Musculo-skeletal anomalies<br>Multiple anomalies<br>Chromosomal disorders<br>Metabolic diseases<br>Urinary tract<br>Other |
| **2. HYPERTENSIVE DISORDERS OF PREGNANCY.** | Pregnancy induced hypertension<br>Pre-eclampsia<br>HELLP syndrome<br>Eclampsia |
| **3. ANTEPARTUM OR INTRAPARTUM HAEMORRHAGE.** After 20 w gestation, whether revealed or not. If associated with PET, APH will be a secondary diagnosis. Ignore minor degrees of haemorrhage (e.g. 'shows', cervical polyps etc). Recurrent bleeding of uncertain origin followed by preterm labour should not be ignored. | Praevia<br>Abruption<br>Uncertain |
| **4. MECHANICAL.** Any death attributed to uterine rupture, deaths from birth trauma or intrapartum asphyxia associated with problems in labour such as cord compression, malpresentation, shoulder dystocia etc.<br>Antepartum deaths associated with cord entanglement in the absence of strong circumstantial evidence that cord compression caused death should be classified as having no associated factor. | **Cord Compression**<br>Prolapse cord<br>Cord around neck<br>Other cord entanglement or knot<br>**Uterine Rupture**<br>Before labour<br>During labour<br>**Mal-presentation**<br>Breech / Transverse<br>Face / Compound<br>Other<br>**Shoulder dystocia** |
| **5. MATERNAL DISORDER.** Specify hypertensive disease present before pregnancy or any other maternal disease or condition sufficient to jeopardise the baby such as diabetes, cardiac disease etc.<br>Infection is classified separately. | Pre-existing hypertensive disease<br>Diabetes<br>Other endocrine conditions<br>Thrombophilias<br>Obstetric cholestasis<br>Drug misuse<br>Uterine anomalies<br>Connective tissue disorders / Other |
| **6. INFECTION**. Confirmed by microbiology / placental histology.<br>Specify maternal infections sufficient to have compromised the baby which may be associated with congenital infection of the baby. Trans-placental transmission may have occurred such as CMV, toxoplasmosis etc.<br>Specify only those ascending infections that are a significant factor in death. Chorioamnionitis sufficient to cause preterm birth may be specified for some neonates but evidence of fetal infection may be required as an explanation of stillbirth. | **Maternal infection**<br>Bacterial / Viral diseases<br>Syphilis /Group B Streptoccus<br>Protozoal<br>Other<br>**Ascending infection**<br>Chorioamnionitis<br>Other |
| **7. SPECIFIC FETAL CONDTIONS.** Document only those specific conditions arising in the fetal period. | Twin-twin transfusion<br>Feto-maternal haemorrhage<br>Non-immune hydrops<br>Iso-immunisation<br>Other |
| **8. SPECIFIC PLACENTAL CONDITIONS.** Specific placental conditions sufficient to cause death or be associated with fetal compromise such as IUGR. These will often be secondary to other maternal conditions e.g. PET.<br>Cord problems associated with compression will normally be classified under 'Mechanical' | Placental infarction<br>Retroplacental haemorrhage<br>Thrombosis in fetal circulation<br>Chorioamnionitis<br>Vilitis<br>Fetal vasculitis<br>Massive perivillous fibrin deposition<br>Vasa praevia / Velementous insertion<br>Other |
| **9. INTRA-UTERINE GROWTH RESTRICTION DIAGNOSIS MADE.** IUGR may be suspected antenatally by abdominal circumference (AC) less than the centile threshold used to define IUGR locally, or decreased AC growth velocity, +/- oligohydramnios. | Suspected antenatally<br>Observed at delivery<br>Observed at post mortem |
| **10. ASSOCIATED OBSTETRIC FACTORS.** Factors recorded as Other Associated Obstetric Factors will be important clinical or pathological features of the pregnancy or baby but will not be an explanation of the death; they will often be secondary to other maternal or fetal conditions. Birth trauma and/or Intrapartum asphyxia should normally be classified primarily by the underlying cause (e.g Mechanical ). Birth Trauma and/or other antenatal/intra-partum factors can be recorded here either as a secondary factor or when there is no underlying explanation. | **Birth Trauma**<br>Intracranial haemorrhage<br>Birth injury to scalp<br>Fracture<br>Other<br>**Intrapartum fetal blood sample <7.25**<br>**Other**<br>Polyhydramnios<br>Oligohydramnios<br>Premature rupture of membranes<br>Spontaneous premature labour |
| **11. NO ANTECEDENT OR ASSOCIATED OBSTETRIC FACTORS.** Deaths with no explanation or significant associated factor. | |
| **12. UNCLASSIFIED.** Cases where little or nothing is known about pregnancy or delivery and which cannot be fitted into any of the above categories. Use as sparingly as possible. | |

## Guidance and Definitions for Completion of Section 13:
## NEONATAL DEATH ONLY

The following definitions and associated subcategories will help you choose the relevant neonatal conditions causing and associated with death

| DEFINITION OF TERMS | Subcategory |
|---|---|
| **MAJOR CONGENITAL ANOMALY.** Any genetic or structural defect arising at conception or during embryogenesis incompatible with life or potentially treatable but causing death. | Central nervous system<br>Cardiovascular system<br>Respiratory system<br>Gastro-intestinal system<br>Musculo-skeletal system<br>Multiple anomalies<br>Chromosomal disorders<br>Metabolic disorders<br>Urinary tract<br>Other |
| **PRE-VIABLE.** Babies (less than 22 weeks) who are non-viable at birth because of gestation but who show signs of life. | |
| **RESPIRATORY DISORDERS.** Severe pulmonary immaturity will encompass those babies where structural lung immaturity is so gross as to mean ventilatory support is unsustainable at the outset, usually babies between 22 – 24w gestation. Surfactant Deficient Lung Disease may include babies with clinical or pathological evidence of hyaline membrane disease. | Severe pulmonary immaturity<br>Surfactant deficiency lung disease<br>Pulmonary hypoplasia<br>Meconium aspiration syndrome<br>Primary persistent pulmonary hypertension<br>Chronic lung disease / BPD<br>Other (includes pulmonary haemorrhage) |
| **GASTRO-INTESTINAL DISEASE.** Many babies with NEC will have associated sepsis which may be given as a secondary cause. | Necrotising enterocolitis (NEC)<br>Other |
| **NEUROLOGICAL DISORDER.** HIE includes those babies with severe hypoxic-ischaemic brain injury before birth. If possible, please specify if HIE was primarily of intrapartum or antepartum origin. Specify periventricular leukomalacia only if this is a significant factor in the infant death. Birth Trauma will usually be classified here. | Hypoxic-ischaemic encephalopathy (HIE)<br>Intraventricular/Periventricular haemorrhage<br>Other |
| **INFECTION.** Where possible specify the location of infection and whether due to bacteria, virus, fungus or other specific organism.<br>If infection was the main cause of death please specify whether infection is congenital (i.e. acquired ante or intrapartum acquired) or neonatal in origin. | Generalised (sepsis)<br>Pneumonia<br>Meningitis<br>Other |
| **INJURY / TRAUMA**. Post natal trauma only including iatrogenic injury. 'Birth Trauma' will usually be classified under neurological disorder e.g. HIE; the obstetric classification identifying the timing of the injury. | |
| **OTHER SPECIFIC CAUSES.** Death due to specific fetal and neonatal conditions such as isoimmunisation or unexplained hydrops. Neonatal conditions will include aspiration, unexplained pulmonary haemorrhage. | Malignancies/Tumours<br>Specific conditions |
| **SUDDEN UNEXPECTED DEATHS.** SIDS should conform to the accepted definition. Unascertained are those unexpected deaths that are not explained despite a full investigation including autopsy, but do not conform to the accepted definition of SIDS. | Sudden Infant Death Syndrome (SIDS)<br>Infant deaths – cause unascertained |
| **UNCLASSIFIED.** Cases where little or nothing is known about the pregnancy or delivery and which cannot be fitted into any of the above categories. Please use this category as sparingly as possible. | |

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